FAMILIES RAISING CHILDREN WITH FASD AND AUTISM IN ONTARIO

by

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Abstract

The current document is a two-paper manuscript-based thesis investigating the experiences of parents raising children with Fetal Alcohol Spectrum Disorder (FASD) and Autism Spectrum Disorder (ASD) in Ontario, Canada. Supports are available in Ontario for families of children with disabilities. However, many parents report that they are not adequately meeting their needs. Therefore, the purpose of this research is to determine what supports parents believe they require to help facilitate adaptation. Both papers used mixed methods, including a qualitative analysis of semi structured interviews and a descriptive statistical analysis of their respective questionnaires. The first paper examined the experiences of parents of adopted adult children with FASD and their needs as they adapted to their children's transition into adulthood. Interpretative phenomenological analysis (IPA) was used to analyze the interviews, and the Questionnaire on Resources and Stress- Friedrich's Version (QRS-F) was examined. Parents described a number of stressors related to their children's transition to adulthood and reported moderate levels of perceived stress. The second paper examined parents' formal and informal support needs as they adapted to raising their middle childhood aged children with ASD and FASD. Thematic analysis was used analyze to the interviews, and the Family Resource Scale as well as the Family Crisis Oriented Personal Scales were administered. Results indicated that there are not enough services to satisfy family needs. Implications for clinical interventions are discussed.

Keywords

The following could be used to describe this thesis entitled "Parents Raising Children with FASD and Autism in Ontario": fetal alcohol spectrum disorder, autism spectrum disorder, developmental disability, families, adaptation, adjustment, mixed methods, Ontario, stressors, capabilities, emergent adulthood, adulthood, middle childhood, services.

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Chapter 1: Introduction

Research regarding families of children with developmental disabilities is necessary in order to ascertain what services are most helpful (e.g., behavioural therapy) for parents to cope with stressors as well as to help determine parents' needs (Glidden, Kiphart, Willoughby, & Bush, 1993). The present study examines the demands and capabilities specifically related to families raising children with Fetal Alcohol Spectrum Disorder (FASD) and Autism Spectrum Disorder (ASD). Raising a child with developmental disabilities has been reported to bring great joy to a family as well as pose unique challenges, which will be explored in further detail (Grace, 1997).

1.1 Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder is an umbrella term that encompasses all manifestations of symptoms related to the in utero exposure of an individual to ethanol (alcohol; Koren & Nulman, 2014; Rasmussen & Bisanz, 2009; Saddok & Saddok, 2007; Streissguth et al., 2004). FASD comprises a continuum of diagnoses including Fetal Alcohol Syndrome (FAS), partial FAS (pFAS), as well as Alcohol Related Effects. Alcohol Related Effects can be co-occurring and include Alcohol-Related Neurodevelopment Disorder (ARND) and Alcohol-Related Birth Defects (ARBD). ARND refers to individuals who have neurobehavioural and/or cognitive impairments but do not experience growth impairments or the facial features associated with in utero exposure to alcohol. ARBD are used to describe various dysplasia or malformations induced by fetal exposure to alcohol (e.g., cardiovascular defects and short palebral fissures; Koren & Nulman, 2014). The diagnostic process is constantly evolving, typically requiring a multidisciplinary team for diagnosis (Chudley, Kilgour, Cranston, & Edwards, 2007; Pei &

Rinaldi, 2004). When estimating the prevalence of FASD in a given population, the changes in diagnostic criteria can pose a barrier (Chudley et al., 2007).

The currently accepted prevalence estimate of individuals with FASD in Canada is 1% of the general population, or 9.1 per 1000 births (Canada FASD Research Network, 2015; Health Canada, 2006). FASD is a lifelong neurodevelopmental disorder, and due to its associated lasting challenges, the annual cost of individuals with FASD in Canada has been estimated to be 7.6 billion dollars (Thanh & Jonsson, 2009). The aforementioned cost includes items such as health care and clinical intervention.

A variety of FASD interventions exist to help children with FASD function better at school and in the home (e.g., cognitive, language, and literacy training; Paley & O'Connor, 2011). It is important to provide support to parents in order to reduce parent-child relationship strains, thereby reducing the risk of negative developmental trajectories (Paley & O'Connor, 2011). Children's behaviours are often misconstrued by parents as intentional rather than a symptom of their disorder, which can lead to parental frustration, anger, and discipline (Malbin, Boulding, & Brooks, 2010; Paley & O'Connor, 2011). Behavioural consultation can help caregivers reframe the behaviours as a result of the neuroteratogenic effects of alcohol on the brain rather than deliberate disobedience, which inspires a more positive parental attitude in addition to a greater understanding of the child's needs (Bertrand, 2009; Paley & O'Connor, 2011).

The concept of viewing the behaviour as a superficial symptom of a physical brain-based disability is called the Neuro-Behavioural (N-B) Model (Malbin et al., 2010). The N-B model posits that brain function is linked to dysfunction and therefore environmental accommodations should be made. For example, it is inappropriate to ask an individual who has linguistic

processing difficulties to follow a long conversation or instructions, because they do not have the required skill set to do so. When individuals have primary disabilities (e.g., linguistic processing) that are not accommodated, the individual's resulting emotions can create a higher risk trajectory for their future, including a higher risk of behavioural problems and psychological disorders (Malbin et al., 2010).

Individuals with FASD may experience primary, secondary, and tertiary disabilities (Malbin et al., 2010; H. Olson, Oti, Gelo, & Beck, 2009; Streissguth et al., 2004). Primary disabilities are defined as those that most clearly reflect primary morphological irregularities as well as underlying brain function or dysfunction (Koren & Nulman, 2014; Malbin et al., 2010; Streissguth & Kanter, 1997). For example, primary disabilities can include dysfunction in adaptive functioning, sensory processing, language comprehension, memory, executive functioning, and facial dysmorphology for individuals with FASD. When the aforementioned issues go unaddressed for an extended period of time, secondary behaviours can arise.

Secondary behaviours are not intrinsic to FASD and evolve over time in the form of defensive behaviours, motivated by a dissonance between the individual's abilities and their environmental expectations (Koren & Nulman, 2014; Malbin et al., 2010). These characteristics can include emotional issues such as low self-esteem, depression, anger, destructiveness, and a feeling of being overwhelmed. These negative emotions can lead to tertiary problems if individuals are unable to address or reduce their secondary disabilities, increasing their propensity to engage in maladaptive behaviours.

Tertiary issues can be understood as the effects of a chronic pattern of secondary defensive behaviours resulting from an individual's inability to respond to the demands of their environment (Malbin et al., 2010). Tertiary problems can include mental health difficulties,

disruptive school experiences, trouble with the law, confinement, inappropriate sexual behaviour, and dependent living (Koren & Nulman, 2014; Malbin et al., 2010; Streissguth & Kanter, 1997; Streissguth, 2007). In order to mitigate some of the aforementioned tertiary issues, it is necessary to create an environment that takes an individual's primary disabilities into account, thereby reducing the need for secondary defensive behaviours and resulting tertiary problems (Malbin et al., 2010; Paley & O'Connor, 2011).

Parents play a pivotal role in managing their children's environment as they are most familiar with their child's/children's strengths and weaknesses. Parents of children with FASD have reported using strategies such as implementing a daily routine to create an environment more conducive to their children's success either at home or in school (Stevens, Nash, Koren, & Rovet, 2012; Watson, Hayes, Coons, & Radford-Paz, 2013). Similar environment shaping techniques have been used for children with Autism Spectrum Disorder (ASD).

1.2 Autism Spectrum Disorder

Like FASD, ASD is a neurodevelopmental disorder characterized by a continuum of symptomatology ranging from mild to severe. In contrast to FASD, ASD is considered a clinical diagnosis and was included in the DSM-IV-TR and DSM-V (American Psychiatric Association, 2000, 2013). Autism Spectrum Disorder is currently characterized by four main criteria. According to the DSM-V, the first required diagnostic criterion is that an individual must exhibit persistent deficits in social communication and social interaction across multiple contexts (American Psychiatric Association, 2013). For example, there must be lack of interest in communication in both the school system and at home.

The second criterion is that there must be restricted and repetitive patterns of behaviour, interests, or activities. Restricted behaviours are exhibited as an intense interest in activities

surrounding a specific topic, resulting in the exclusion of other behaviours. For example, some children with ASD take a keen interest in machinery and only want to participate in activities that pertain to that subject. Repetitive behaviours include mannerisms like hand flapping, or rocking.

The third criterion is that symptoms must be present in the early developmental period and the fourth criterion dictates that the symptoms cause clinically significant impairment in social, occupational, or other important areas of functioning. Furthermore, the symptoms cannot be better explained by another psychological disorder like intellectual or communication disabilities. All individuals with ASD manifest the aforementioned four characteristics to some degree.

ASD has a prevalence rate of approximately 1 in 88 children in North America (American Psychiatric Association, 2013; Hall & Graph, 2012). The cost of services for families of children with ASD also ranges depending upon their child's diagnosis, but the average Canadian middle class family cannot financially afford to support their children without government assistance (Dudley & Emery, 2014). For example, one commonly required service that is at least partially funded by the Canadian government is Applied Behavioural Analysis, which is the gold standard for behavioural intervention for individuals with ASD (Kopellman, Lindgren, & Wacker, 2015; Ontario Ministry of Children and Youth Services, 2011). Not all individuals with Autism require the same services due to the range of manifested symptoms (Chaplin, 2007).

Individuals with FASD or ASD have individualized needs associated with the severity of their disability (Brown & Bednar, 2003; Chaplin, 2007). How parents adapt to the needs of their child with FASD or ASD is dependent upon factors such as coping skills, resources, and how

they perceive their needs (Glidden et al., 1993). The subsequent section discusses a theoretical framework useful for understanding the aforementioned issues and their contribution to family adaptation.

1.3 The Family Adjustment and Adaptation Response Model

One model used to examine the adaptation capabilities of parents raising children with disabilities is the Family Adjustment and Adaptation Response Model (FAAR), which entails three social systems: the individual, the family, and the community (Patterson & Garwick, 1994a, 1994b, 1998; Patterson, 1988). This model theorizes that the family attempts to retain good family functioning (homeostasis) by employing coping skills and resources (i.e., capabilities) to minimize any negative effects from stressors and/or strains (i.e., demands) (Patterson, 1988). Capabilities are derived from any of the three social systems. Figure 1 below illustrates the FAAR model.

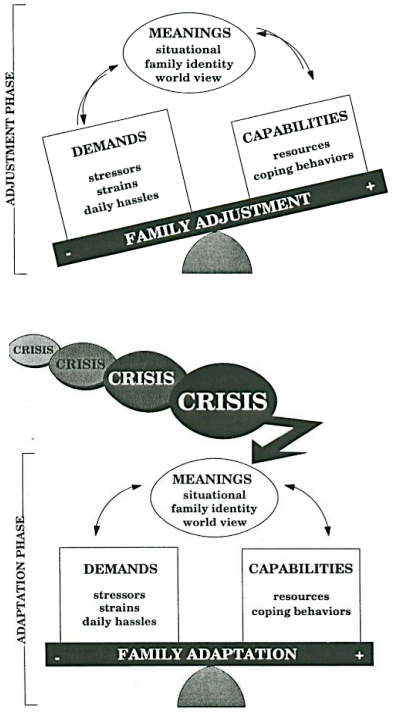

Figure 1: The Family Adjustment and Adaptation Response Model
(Patterson & Garwick, 1994a, 1994b)

Capabilities are comprised of two factors. The first is resources, which are what a family has access to physically and socially as well as characteristics, traits, or competencies. Resources can be tangible, like money, or intangible, like a personality trait or relationships. The second capability factor is referred to as coping behaviours, which are the actions, either overt or covert, that a family takes to deal with a given demand. The more demands a family is contending with, the more capabilities are required to balance out the demands.

Within the FAAR model, demands are defined as any "condition or stimulus that produces or calls for change in the family system" (Patterson, 1988, p.210). Demands include stressors and strains. A stressor can be defined as a transition or event that can potentially produce a change in the family social system (e.g., boundaries, goals, and values; McCubbin & Patterson, 1983). A strain emerges insidiously into the family and has no discrete onset. Strains emerge when there is an inability to completely resolve a stressor, or when there is a dissonance between families members' role expectations (Patterson, 1988). For example, a parent who is depressed due to unresolved demands may experience the strain of marital conflict. Sometimes a strain can become severe enough that it becomes a stressor in and of itself, creating a pile up effect. Marital conflict is one example of a strain that can increase the likelihood of a stressor like divorce (Patterson, 1988). A pile up of strains and stressors can lead to family tension, and then to perceived parental stress if they remain unresolved. McCubbin and Patterson (1983) define family tension as a state in which family members believe there is a demand-capability imbalance in the family's functioning.

The FAAR model has two phases that are divided by a crisis event (Patterson & Garwick, 1994b; Patterson, 1988). The first phase is the adjustment phase, which can be characterized as a relatively stable period in family functioning when families are generally capable of meeting the

demands with their existing capabilities, thereby resisting any major changes in the family system. There are only minor changes made in family dynamics. For example, an eldest child may have to do more chores to assist the mother during pregnancy, but the child's role remains essentially the same.

When a demand-capability imbalance occurs and the family's capabilities are overwhelmed by demands, family functioning becomes unstable. An event that upsets the equilibrium of the family social system is referred to as a state of crisis (Patterson, 1988). It should be noted that a crisis does not imply only a negative event, but an event that changes the pattern of family functioning or communication, and normative crises are expected across the lifespan. For example, the adoption of a child may be considered a joyous occasion for the adoptive parents, but is considered a 'crisis' in the FAAR model due to the required shift in family roles and needs.

After a crisis occurs, families enter the second phase of the model called the adaptation phase. During the Adaptation phase, families attempt to re-establish good family functioning. In order to equalize the demand/capability imbalance, the family must make changes to either enhance their capabilities or to reduce the demands. For example, when an adopted child enters the home, it is a common practice for the adoptive parents to take parenting classes to increase their coping skills (Adopt Ontario, 2010). According to the FAAR model, bolstering parents' coping skills and resources facilitates a balance between their capabilities and the demands placed upon by them by their children, reducing parents' perceived stress levels.

A family's efforts to achieve homeostasis are referred to either as family adjustment or family adaptation, both of which are on a continuum ranging from good to poor (Patterson, 1988). A mediator in the family's ability to cope, both before and after the crisis, is the meanings

they attribute to the people and events in their lives (McCubbin & Patterson, 1983). There are two levels of meaning families can make: situational and global. Situational meanings pertain to a family's demands, their capabilities and how they interrelate (Patterson, 1988, 1993). For example, the same demand may be stressful for one parent and not another due to a difference in their perceptions of it. Global meanings define how family members view their relationship with each other, and their view of how the family unit relates to the community (Patterson, 1993). Due to the implications of meanings and their impact on parents' perceived stress levels, they are often a focus of qualitative research and clinical intervention (Thompson, Hiebert-Murphy, & Trute, 2013).

According to the FAAR model, families are in constant cyclical movement between the adjustment and adaptation phases, which is considered a normative process. However, problems emerge when families fall into the maladaptive end of the adaptation continuum, and experience stress as a result (Glidden, Billings, & Jobe, 2006). Families who experience difficulty with adaptation often require additional support from the community to help strengthen the coping skills and resources they already possess as a family system (Fontenot, 2007; Jones & Passey, 2004). The demands and capabilities of families, including adoptive families, raising children with developmental are discussed in the subsequent sections.

1.4 Raising a Child with Developmental Disabilities across the Lifespan

All families encounter demands, but parents of children with developmental disabilities face some unique difficulties in addition to the stressors encountered in families who do not have a child with a developmental disability (Dyson, 1993; Fidler, Hodapp, & Dykens, 2000; Goudie, Narcisse, Hall, & Kuo, 2014; Hodapp, Dykens, & Masino, 1997; Jones & Passey, 2004). These stressors may include a lack of information regarding the developmental disability, maladaptive

externalizing behaviours, and the transition into adulthood (Briskin & Liptak, 1995; Ellis et al., 2002; Fidler et al., 2000). Although the aforementioned stressors have been reported by parents of children with developmental disabilities in general, stressors can differ according the type of disability, highlighting the importance of investigating specific diagnoses (Auyeung, Burbidge, & Minnes, 2011; A. Perry, 2005; Walker, Van Slyke, & Newbrough, 1992). Additionally, as children with developmental disabilities grow and transition through each developmental stage, demands and capabilities often change, which can also be perceived as stressful by parents (Auyeung et al., 2011; White, McMorris, Weiss, & Lunsky, 2012). This section discusses specific stressors (i.e., demands) parents encounter when raising a child with a developmental disability, as well as the supports (i.e., capabilities) available in Ontario that can be used to address those stressors, thereby facilitating adaptation.

1.4.1 Demands. One stressor for parents, particularly when their children are young, is a need for information regarding their children's disabilities (Wodehouse & McGill, 2009). Parents who lack information regarding their child's disability report higher levels of perceived stress (Ellis et al., 2002). Parents' lack of knowledge can also lead to a sense of helplessness (Ellis et al., 2002). In one study by Ellis et al. (2002), 47.1% of parents of children with Autism, Pervasive Developmental Disorder and Intellectual disability rated a need for information as the area in which they most 'definitely need help'.

Early diagnosis is important for providing parents with the knowledge of what to expect from their children, and for providing information regarding early intervention (Watson, 2008a, 2008b; Watson, Hayes, & Radford-Paz, 2011). However, obtaining a diagnosis can in itself be a stressor if the child is diagnosed with a less socially accepted disability (e.g., FASD), if the diagnostic process is lengthy, or if professionals are not adequately educated with regards to

disability related diagnostic criteria (Watson, 2008b; Watson, Hayes, et al., 2013). For the aforementioned reasons, parents' diagnostic experiences often vary according to their child's type of developmental disability (Watson et al., 2011).

A third predictor of perceived family stress is the presence of externalizing behaviours, which may also be linked to the type of developmental disability. It has been reported that scores on the Child Behaviour Checklist (i.e., behaviour severity) are positively correlated with the overall stress levels of parents (Hall & Graph, 2012; Hodapp et al., 1997; Ingersoll & Hambrick, 2011). Externalizing behaviours such as aggressive behaviours (e.g., yelling or physical altercations) have been highlighted in the research as particularly stressful for parents (Fidler et al., 2000; Hall & Graph, 2012; Hodapp et al., 1997).

Maladaptive behaviours have been found to be one of the leading stressors for a range of developmental disabilities such as Autism, FASD, and Prader-Willi syndrome (Hall & Graph, 2012; Hodapp et al., 1997; Jirikowic, Olson, & Astley, 2012). Parents of children who exhibit ASD related maladaptive behaviours tend to report some of the highest clinically significant levels of perceived stress in comparison to parents of children with other developmental disabilities (Hayes & Watson, 2013; Watson, Coons, & Hayes, 2013). However, recent research indicates that parents of children with FASD report even higher levels of perceived stress than do parents of children with ASD (Watson, Coons, et al., 2013).

It is common for children with developmental disabilities like ASD and FASD to be on at least one medication for the purpose of reducing the likelihood of aggressive or hyperactive behaviours (Doig, McLennan, & Gibbard, 2008; Hall & Graph, 2012; Witwer & Lecavalier, 2005). Medical conditions may also intensify maladaptive behaviours, and parents have reported that a higher number of medications is associated with the child exhibiting an increased number

of behavioural problems (Hall & Graph, 2012; Witwer & Lecavalier, 2005). It is important for parents to work closely with mental health professionals in order to monitor any changes in behaviour, so that behaviour management strategies can be put in place (e.g., a change in medication or behavioural therapy).

Behavioural phenotype research is a useful practitioner tool for providing the appropriate support (e.g., ABA training for Autism) to parents for their children's maladaptive behaviours (Fidler et al., 2000). However, it should be noted that parents are cautioned against holding stereotypic beliefs or behavioural expectations because not all children show a manifestation of a behavioural phenotype, and parents may be disappointed if the stereotypes do not hold true for their child's disability (Glidden, Grein, & Ludwig, 2014). For example, not all children with ASD have savant-like abilities. Parents whose children do not fit the behavioural phenotype for their respective disorder will have to find new and alternative methods for raising their child and managing their behaviours.

Regardless of whether or not individuals with disabilities fit a behavioural phenotype, many require support services throughout their lifetime (Olson et al., 2009; Vogan et al., 2014). Transitioning through developmental stages is often perceived as stressful for both children and their parents, due to increased demands, such as changes in access to resources (Kim & Turnbull, 2004; Michaud & Temple, 2013; S. Olson, Sameroff, Lunkenheimer, & Kerr, 2009). For example, in Ontario, individuals with disabilities are required to switch into the adult formal service system at the age of 18. Services such as the Ontario Disability Support program (ODSP) can provide basic financial support and medical benefits (Ontario Ministry of Community and Social Services, 2012). Parents who believe they are lacking in the necessary adult support services fear negative outcomes for their children's futures, and experience feelings of stress

(James Williams, Dubovsky, & Merritt, 2011; Michaud & Temple, 2013; Watson, Coons, et al., 2013).

1.4.2 Capabilities. There is research evidence supporting specific resources that can assist families in re-establishing the balance of their demands and capabilities, thereby helping them move from the adjustment to the adaptation phase of the FAAR (Patterson, 1988). Research had begun to move from examining solely family stressors to investigating resilient parents to identify their strengths (Patterson, 2002b). For example, social support, individual differences, financial stability, and support services are several resources that bolster a family's capabilities, and assist in mediating the effects of the stressors outlined in the previous section (Cantwell, Muldoon, & Gallagher, 2014; Doig, McLennan, & Urichuk, 2009; Ellis et al., 2002; Manning, Wainright, & Bennett, 2011; Watson, Coons, et al., 2013; Wei et al., 2012).

Despite often numerous demands, many families of children with developmental disabilities retain a healthy level of family harmony irrespective of the additional stressors associated with raising a child with developmental disabilities (Perry, Harris, & Minnes, 2004). A study by Perry at al. (2004) indicated that families of children with developmental disabilities within their sample closely resembled healthy families more often than distressed families in regards to stressors and family harmony ratings. They found that families of children with disabilities generally fared as well as families without disabilities on those measures. A caveat to the study is that the sample may not be representative of all families because extremely stressed parents may not have participated; however, research of this nature provides a more balanced outlook for these families (Perry et al., 2004).

Resilient families have consistently rated social support as one of the most important resources for adapting to their children's developmental disabilities (Ainbinder et al., 1998;

Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Maul & Singer, 2009; White & Hastings, 2004). Parent to parent support has been rated by parents as a particularly useful form of social support, and occurs when a parent who has a child with a developmental disability is matched with another family who has a child with the same disability (Ainbinder et al., 1998; Frost Olson et al., 1999; Kerr & McIntosh, 2000). One benefit of parent to parent support, as opposed to a clinical relationship, is that the parents have 24 hour access to each other, and in time the relationship becomes a mutual exchange of information and emotional support (Ainbinder et al., 1998; Kerr & McIntosh, 2000; Maul & Singer, 2009)

Parent to parent support relationships offer a large range of other benefits. For example, they provide a sense of sameness or normalcy, which reduces feelings of isolation (Ainbinder et al., 1998; Kerr & McIntosh, 2000; Maul & Singer, 2009). There is also the opportunity for the transference of practical skills and knowledge pertaining to a specific disability (Ainbinder et al., 1998; Kerr & McIntosh, 2000; Maul & Singer, 2009). Seeing the positive aspects of another family's life with an older child with a developmental disability can also help parents formulate new and more positive ideas for the future of their own child (Ainbinder et al., 1998; Kerr & McIntosh, 2000; Maul & Singer, 2009). The parent to parent relationship can also improve emotional well-being as well as increase levels of optimism (Ainbinder et al., 1998; Kerr & McIntosh, 2000; Maul & Singer, 2009).

Optimism and positive attitude were found to be invaluable parent traits for adapting to raising children with developmental disabilities (Li-Tsang, Yau, & Yuen, 2001). It has been found that parents who hold positive perceptions of themselves, their family members, and stressful situations were better able to formulate coping strategies than parents who did not (Ellingsen, Baker, Blacher, & Crnic, 2014; Hastings & Taunt, 2002; Li-Tsang et al., 2001; Peer

& Hillman, 2014; Thompson et al., 2013). Additionally, positive cognitive appraisals (i.e., the meanings) made about stressors allow parents to view demands like maladaptive behaviours more positively (Glidden et al., 2006; Thompson et al., 2013). For example, parents who hold the perception that they are in control of a difficult situation often experience less intense feelings of hopelessness and depression than parents who do not believe they are in control (Jones & Passey, 2004). Research has shown that increased optimism and positive appraisal can decrease perceived parental distress, thereby improving family functioning (Ellingsen et al., 2014; Thompson et al., 2013)

Li Tsang et al. (2001) examined family traits in addition to parental traits. It was found that a higher education level, little financial difficulty, and a stable family structure were most conducive to positively adapting to a child with developmental disabilities (Fountain, Winter, & Bearman, 2012; Li-Tsang et al., 2001; Paley, O'Connor, Frankel, & Marquardt, 2006). The financial difficulties were often alleviated by fathers working increased hours per week (Ellis et al., 2002; Willoughby & Glidden, 1995). The strain of additional working hours and other stressors was offset by strong and stable marital relationships that can provide social and emotional support (Kersh et al., 2006; Risdal & Singer, 2004; Willoughby & Glidden, 1995).

When parents require additional support than what they can provide to each other as a couple, they often turn to formal services like respite care (Doig et al., 2009; Dunbrack, 2003). Parents of children with developmental disabilities who express aggressive externalized maladaptive behaviours are in particular need of respite care, and parents whose children utilize that service report long lasting improvements in their psychological wellbeing (Hodgetts, Nicholas, & Zwaigenbaum, 2013; Mullins, Aniol, Boyd, Page, & Chaney, 2002; Strunk, 2010). For a complete description of the formal services available in Ontario, please see the manuscript

titled “Waving a magic wand: Supports for Families Raising Children with ASD and FASD in Ontario.” When a family uses services and personal resources to strengthen their capabilities in the adjustment stage of the FAAR, they begin to transition into the adaptation phase, as homeostasis is restored between their demands and capabilities (Patterson, 1988).

1.4.3 Transitioning from adjustment to adaptation. Parents can experience post-traumatic growth in the face of their struggles to cope with feelings of uncertainty, anxiety, and/or depression (Lindstrom, Voynow, & Boyer, 2013; Zhang, Yan, Du, & Liu, 2013). Post-traumatic growth refers to the positive changes parents experience as a result of their efforts to cope with a challenging situation (Jayawickreme & Blackie, 2014; Zhang et al., 2013). For example, parents of children with ASD have reported growth in areas including personal strength, their appreciation of life, spirituality, and a better ability to perceive to new possibilities (Zhang et al., 2013). The range of factors that facilitate post-traumatic growth are currently debated in the literature. One contributing factor is deliberate rumination, which is the control of thoughts focused on problem solving, making sense of the situation, and reminiscence of positive events (Zhang et al., 2013). Factors associated with post-traumatic growth are useful for both parents and clinicians to inform their efforts towards facilitating adaptation (Jayawickreme & Blackie, 2014; Lindstrom et al., 2013; Zhang et al., 2013).

The aforementioned literature review focuses primarily on birth families of children with developmental disabilities, and there appears to be a general lack of research regarding adoptive parents in comparison to that body of research (Camarata, 2005; Griffith, Hastings, Nash, & Hill, 2010). There is also a lack of research regarding adopted individuals with FASD in Ontario, regardless of the high estimate of FASD within the child welfare population, which was estimated to be up to 11% (Popova, Lange, Burd, & Rehm, 2014). The topic of adoption is

important to address because it poses unique challenges that are described in the subsequent section.

1.5 Adoption of Children with Developmental Disabilities

Adoption can be defined as a two-step legal transfer, in accordance with provincial statutory provisions, of all "parental rights and responsibilities that a biological parent has to a child, to the adoptive parent(s)" (Burge, 2008, p.25). Historically, children with developmental disabilities were considered to be unadoptable (Bohman, 1970). Children with developmental disabilities were considered too 'difficult' to adopt and as a result, it was difficult for adoption agencies to find an appropriate adoptive family match (Bohman, 1970). The difficult child perspective began to shift in the 1970's as researchers like Coyne and Browne (1985) found much lower disruption rates than was previously believed, meaning that very few adoptions were terminated before they were legalized.

Currently a wealth of research supports a high rating of parental satisfaction and success in adoptive families of children with developmental disabilities including Down syndrome and FASD (Glidden & Cahill, 1998; Glidden & Johnson, 1999; Glidden, 2000; Lightburn & Pine, 1996; Olson et al., 2009; Rosenthal, Groze, & Aguilar, 1991). Glidden and Johnson (1999) conducted a study in which adoptive parents reported a generally good outcome after 12 years of raising a child with a developmental disability. In addition, the adoption of multiple children with developmental disabilities has also been rated as highly satisfactory (Glidden, Flaherty, & Mcglone, 2000; Glidden, 2000). That is not to say that those adoptive families do not experience any difficulties and do not need additional resources (Glidden, 1990).

Although there is research available regarding families of adopted children with developmental disabilities, there is a lack of research regarding parents of adult children in

general (Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008; Minnes, Woodford, & Passey, 2004; Minnes & Woodford, 2004; Penny, Borders, & Portnoy, 2007). Adopted adult children are no longer eligible for Children's Aid Society related services when they reach the age of majority, and they must apply to Ontario's adult service system to continue receiving support, which can be a confusing process for parents (Osgood, Foster, & Courtney, 2010). Despite the inability of parents to retain legal control of their children, it is common for children to remain in residence with their parents, and to remain at least partially dependent on their resources (Clark et al., 2008; Streissguth & Kanter, 1997).

Lifelong access to supports are considered extremely important in maintaining the demand-capability balance in a successful adoption, and it is for that reason that families must meet specific financial requirements before they are eligible for adopting a child in Ontario (Adopt Ontario, 2010). Resources beyond monetary funding are also rated as highly important by adoptive parents including access to information regarding the developmental disability, medical assistance, therapy, and appropriate school programs (Glidden & Cahill, 1998; Lazarus, Evans, Glidden, & Flaherty, 2002; Perry & Henry, 2009; Rosenthal et al., 1991).

Despite the importance parents ascribed to obtaining information, there appears to be a lack of information access not only with issues of abuse but also with regards to medical and diagnosis information (Falhberg, 1997; Perry & Henry, 2009; Silverstein, 1997). It can be difficult to access information for cases in which diagnoses can be a challenge, such as diagnosing FASD or developmental disabilities in international adoptions (Lazarus et al., 2002). Parents who do not have the appropriate information about the developmental disability report increased levels of perceived stress (Lightburn & Pine, 1996). When parents lack the appropriate disability related information, they may feel as if they are lacking in the skills required to

overcome any disability related obstacles (e.g., externalizing behaviours), resulting in an increase in perceived stress levels (Lightburn & Pine, 1996).

Adoptive parents reported that social support is necessary for advice in situations for which they require additional information, and for general emotional support (Glidden et al., 2006; Platz, 2004). Social support can come in the form of community acceptance as well as the quality of relationships of family members, significant others, teachers and medical professionals (Glidden et al., 2006; Glidden & Johnson, 1999; Perry & Henry, 2009). It is important for medical professionals to acknowledge the expertise of adoptive parents concerning their child's well-being as well as the family's expectations for the child in order for the most effective treatment to be provided (Lightburn & Pine, 1996). Adoptive parents are the biggest advocates for their children with development disabilities, and supportive relationships with community members and medical professionals can help facilitate their pursuit of goals for their children (Foti-Gervais, 2006; Lightburn & Pine, 1996).

Adopted children may require professional intervention because they are particularly at high risk for Post-Traumatic Stress Disorder because they are commonly maltreated (Hansen, 2007). It can be difficult for clinicians to provide therapy to children for cases of abuse or stressful living environments because it is common for adoption agencies, in both the United States and Canada, to label children as 'abused' and omit specifications about the occurrence(s) (CanadaAdopts, 2001; Kopels, 1995; Silverstein, 1997). Parents are cautioned to find out as much as they can before adoption (CanadaAdopts, 2001). The lack of specific information regarding abuse is a problem because adoptive parents require specific training to help provide the appropriate emotional (i.e., boundaries) and environmental support (i.e., establishing a

feeling of safety) in order to foster positive relationships with their adopted children (Silverstein, 1997).

Attempting to discern the causes of problematic behaviours can also be difficult for adopted children who have developmental disabilities and have been abused by other foster parents, adoptive parents, or birth parents (Silverstein, 1997). A history of child abuse can lead to attachment difficulties which, if left untreated, could contribute to problems in establishing permanent adoptive placements (Nalavany, Ryan, Howard, & Smith, 2008; Silverstein, 1997). Children are often at a high risk for psychological disorders such as Post Traumatic Stress Disorder and other anxiety disorders (e.g., specific phobia), or attention related disorders (Gagnon-Oosterwaal et al., 2012; Nalavany et al., 2008). Symptoms of the aforementioned psychological disorders can have extremely similar behavioural manifestations, and therefore it is important to have knowledge of a child's history in order to understand the context of their behaviours for the administration of an appropriate treatment (American Psychiatric Association, 2013; Leyfer et al., 2006).

1.5.1 Adopting children with FASD. A need for history information is particularly true for the FASD adoptive population, and there a disproportionate number of individuals in foster or adoption care with FASD in Canada in comparison to birth families (Stade et al., 2009). In 2014, it was estimated that there were 612 to 2,096 children with FASD within the child care system in Ontario, which is 6 to 11 percent of that population (Popova et al., 2014). The large range in estimation of the child welfare FASD population is partially caused by a difficulty obtaining a diagnosis due to a lack of information. Many individuals remain unidentified in the system, making the calculation of an accurate prevalence rate extremely difficult.

The typical lack of information on adopted children's biological families is particularly problematic for the FASD adoption population because it can be difficult to confirm maternal drinking during pregnancy, which is often a requirement for diagnosis (James Williams et al., 2011). Additionally, as individuals with FASD age, any disability related facial features are diminished, compounding the diagnostic difficulty (Chudley, 2008; Chudley et al., 2005; Streissguth, 1994; Wheeler & Temple, 2013). FASD does not always manifest facial features and is often considered an invisible disability, and therefore any related problematic behaviours may be misconstrued as intentional rather than related to their disability (Chudley, 2008).

FASD related behaviours may also be missed because they are instead attributed to comorbid psychological disorders like ADHD, which is the most common comorbidity with FASD (Doig et al., 2008). As was aforementioned, the adoption population has a high psychological comorbidity rate (Gagnon-Oosterwaal et al., 2012). FASD also shares similarities with ASD symptoms, and it can be difficult to distinguish between the two (National Organization on Fetal Alcohol Syndrome, n.d.).

1.6 Raising Children with FASD and Autism

Autism and FASD share some characteristic similarities including social and communication deficits, as well as a propensity to exhibit a higher number of maladaptive behaviours (Minnesota Organization on Fetal Alcohol Syndrome, 2015; Mukherjee, 2011). Parents of children with FASD have discussed a perceived lack of services in Ontario for individuals with FASD compared to other neurodevelopmental disabilities like ASD, despite similar possible deficits and lifelong implications (Brown & Bednar, 2003; Watson, Hayes, et al., 2013). The similarities and differences between ASD and FASD will be briefly reviewed, and related supports available in Ontario will be discussed.

1.6.1 Similarities between FASD and Autism. One of the most significant similarities between FASD and Autism is the parallel in social difficulties (Bishop, Gahagan, & Lord, 2007; Minnesota Organization on Fetal Alcohol Syndrome, 2015; Stevens et al., 2012). Due to issues with self control and difficulty learning social skills, socially inappropriate behaviours for their respective age group and difficulty interacting with peers are common to both disabilities (Bishop et al., 2007; Stevens et al., 2012). Specifically, children with ASD and FASD have a tendency to either ignore the person they speak to, or to interact with researchers in a negative fashion (Stevens et al., 2012). Social deficits also vary with where the individuals are on their respective disability spectrum, according to their Intelligence Quotient, and in accordance with their neurobiology (Kully-Martens, Denys, Treit, Tamana, & Rasmussen, 2012). Preliminary research has indicated that individuals with FASD may struggle with Theory of Mind, which is the capacity to understand that others have thoughts and beliefs, and is commonly underdeveloped in the ASD population (Rasmussen, Wyper, & Talwar, 2009).

The second similarity between ASD and FASD with regards to symptomatology is a tendency to exhibit maladaptive externalizing behaviours (Bishop et al., 2007; Stevens et al., 2012). Examples of commonly expressed behaviours are aggressive actions, hyperactivity, self injury, or suicidal behaviours (Bishop et al., 2007). These behaviours are often present to some degree across the lifespan (Coons, 2013; Dudley & Emery, 2014). The difficulties with social interaction and externalizing behaviours contribute in part to some of the highest perceived parental stress levels in developmental disabilities literature, and parents often require supports to contend with those issues (Hayes & Watson, 2013; Watson, Coons, et al., 2013).

1.6.2 Supports for individuals with FASD and ASD. Many parents report that Ontarian supports are not adequately meeting their needs (Doig et al., 2009; Dunbrack, 2003; Watson,

Hayes, et al., 2013; Watson, 2008a). Supports are available for families of children with disabilities in Ontario including respite care, social support groups, and diagnostic services. For example, in a study of families with ASD and FASD, parents of children with both diagnoses reported a need for professionals to receive more education regarding disabilities (Watson, Hayes, et al., 2013). Although parents of children with ASD report a need for additional services, parents of children with FASD are particularly lacking in knowledgeable professionals and resources, especially in Ontario (Brown & Bednar, 2003).

Ontario is one of the only provinces lacking an FASD initiative addressing the needs of families of children with FASD, and the Provincial Government of Ontario has recently been creating an FASD strategy to address the need for service support (Parliamentary Assistant Granville Andersib, 2015). A round table report was developed by FASD experts across the province. Of note, the FASD strategy includes adults with FASD and their respective services, an issue seldom discussed in the literature (Parliamentary Assistant Granville Andersib, 2015; Wheeler & Temple, 2013). The FASD strategy has also included the education system, which is generally lacking in FASD related training (Ministry of Education, 2015). FASD provincial initiatives are not only important for ensuring that the needs of families impacted by FASD are met, but also to promote FASD prevention. The impact of the provincial government's efforts to implement the recommended strategies remains to be evaluated.

1.7 Purpose of the Research

The purpose of this study is to identify the experiences of parents raising children with FASD and ASD, with a specific focus on families' demands and the supports they require to contend with them. As was aforementioned, there exists a limited a body of research conducted within the United States regarding issues adoptive parents typically face, such as adoption

satisfaction, perceived parental stress, and family resources (e.g. Glidden 2000; Glidden & Cahill,1998; Lazarus et al., 2002; Rosenthal et al., 1991). However, there appears to be very little research on the experiences of Canadian adoptive families. Canadian resources with regards to services and financial supports are available in Ontario for parents who have adopted children with disabilities; yet little detail is known about the actual needs of those families (Adopt Ontario, 2010). There is even less research pertaining to adopted adult children with developmental disabilities (Wheeler & Temple, 2013).

Middle childhood is another age group for which there is little research, and existing studies present mixed results with regards to parent's levels of adaptation (Neece, Green, & Baker, 2012; Woodman, 2014). A lack of resources in early childhood has been highlighted as one factor associated with increased parental stress (Azad, Blacher, & Marcoulides, 2013). Supports are important for long term adaptation throughout middle childhood, but more information is required about what supports parents require in Ontario (Neece et al., 2012).

Additionally, there is limited research comparing differences in adaptation between families of children with different types of developmental disabilities. Studies have been conducted comparing parental stress ratings for different developmental disabilities (Azad et al., 2013; Gupta, 2007; Watson, Coons, et al., 2013). For example, a study by Gupta (2007) found evidence that parents of individuals with ADHD and/or developmental disabilities reported higher levels of perceived parental stress than was experienced by parents of children with medical complications and typically developing children. Parents' elevated stress levels appear to be associated with disability related demands like externalizing behaviours, because the type of caregiver (i.e. biological versus adoptive) was not a specific predictor for stress level (Gupta, 2007). In other words, the type of disability and its associated behaviours impact heavily on the

caregiver, yet little research has been conducted to look at the differences between disability types in families. For example, ASD and FASD are disabilities associated with some of the highest levels of perceived parental stress due to issues such as children's externalizing behaviours, a lack of public understanding about the disability, and limited available services, but there is limited research comparing the two disabilities (Watson, Coons, et al., 2013; Watson, Hayes, et al., 2013). More research is needed in regards to how and why or why not families are able to cope with the demands of their children's specific developmental disability.

There is also an absence of qualitative research addressing the experiences of parents raising children with FASD in Ontario across their children's lifespans (Wheeler & Temple, 2013). A lack of qualitative research is problematic when trying to understand the context of parents' experiences (Coyle, 2007). For example, it has been recognized in the literature that some parents experience high levels of perceived stress (e.g., Hall & Graph, 2012; Jirikowic et al., 2012; Michaud & Temple, 2013), but it has not been established that a high level of stress is experienced across all situations or their child's lifespan. Qualitative research, interpretive phenomenological analysis in particular, can assist with gaining an understanding the context of adoptive parents' experiences, and can assist in understanding their personal meanings ascribed to adaptation.

The lack of knowledge surrounding the needs of parents of children with FASD is problematic given that early intervention is essential for mitigating the development of secondary disabilities (Chudley et al., 2007; Streissguth et al., 2004; Streissguth, Barr, Kogan, & Bookstein, 1997). Individuals with Autism and FASD can share similar symptomatology and secondary disabilities, often remaining within the home in adulthood, meaning parents are central figures throughout their children's lives (Clark et al., 2008; Streissguth et al., 1997; Vogan et al., 2014).

Parents can act as protective factors for moderating secondary disabilities, and the gathering of resources promotes parents' adaptation to their children's needs (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Macmullin, Tint, & Weiss, 2011; Nachshen & Minnes, 2005; Streissguth et al., 2004). Therefore, more information is required regarding parents' needs to address any service gaps to strengthen their capabilities, thereby facilitating bonadaptation.

The present study is part of a larger project whose aim is to identify families' demands and capabilities as they adapt to raising their children with developmental disabilities in Ontario, Canada. Children's transition through the developmental stages can be a potential source of perceived stress for parents of children with disabilities (Kim & Turnbull, 2004; Michaud & Temple, 2013; S. Olson et al., 2009). Therefore, the purpose of this research is to determine what supports parents of children with FASD and ASD believe they require to help them transition into the adaptation phase of the FAAR.

1.7.1 Research questions. The current study aims to answer the following research questions:

1. What is the lived experience of parents raising children with FASD and ASD in Ontario?

    a) Are parents' experiences consistent with the existing, though limited, literature?

    b) How are parents adapting to the demands associated with their children's transition into the next developmental stage? (i.e., middle childhood or adulthood?)

2. What supports do parents require to facilitate bonadaptation?

a) What supports do parents of adult adopted children with FASD require as they transition into adulthood?

b) What supports do parents of school age children with ASD and FASD require?

1.8 Reflexivity

An integral foundation of qualitative research is the concept of the 'researcher as research instrument' (Patton, 2002; Pezalla, Pettigrew, & Miller-Day, 2012). Reflexivity involves the practise of "examining oneself both as researcher, and the research relationship" (Hsiung, 2010, para.1). A researcher's background determines why and how they conduct their research, and influences what they choose to investigate (Malterud, 2001). In order to promote self-reflexivity, a researcher must present and acknowledge the influence of their own ethnicity, gender, religion, and values on the interpretation of their research, and their understanding of the phenomena being examined (Merriam, 2002). The following is a description of my personal and professional background, and how they may have influenced the conclusions made in my research.

The inspiration for my current research began with my first involvement with families of individuals with developmental disabilities, which began with two consecutive years of working at a summer camp for children with developmental disabilities (e.g., ASD, Cerebral Palsy and Down syndrome). I had the opportunity to talk with parents about their triumphs and difficulties experienced when raising their children with developmental disabilities. In addition to my work at the summer camp, I worked for one summer as a respite worker. I was acutely aware of how valuable respite care services were to the individuals I worked with, and was made aware by parents of the scarcity of resources for families with children with developmental disabilities. The topics of services and practical issues were surprisingly not raised during the developmental courses of my undergraduate psychology degree. I wanted to learn more. Parents'

resourcefulness in the face of, at times, great hardship inspired me to apply to work under the supervision of Dr. Shelley Watson for my Master's in Applied Psychology degree.

Dr. Watson has had a great influence on my work. Dr. Watson's focus on the positive aspects of raising individuals with developmental disabilities has balanced my perspective as a researcher, which previously focused exclusively on negative characteristics (e.g., parenting stress). Maintaining a positive lens has, at times, been a source of struggle. I think I particularly struggled with a negative lens when working with FASD and ASD populations, both associated with the highest levels of perceived parenting stress (Watson, Coons, et al., 2013). I viewed these populations as being in the greatest state of need, and was consequently drawn to them for my research. Balancing both the positive and negative aspects of raising children with developmental disabilities has improved the quality of my research by allowing me to paint a more accurate picture of parents' experiences. Acknowledging the 'positives' has also impacted my clinical work with families of children with disabilities.

As part of my Master's degree I was required to complete a 400-hour clinical psychology placement during my second year, which I completed at the Child and Family Centre in Sudbury. I had the opportunity again to work with children with developmental disabilities and their families. The themes of my interviews were echoed in the parent clients I worked with, who showed great strength in the advocacy efforts made for their children. I was also stricken by how much I required the parents' insights when working with their children, and how parents are the experts in both their own and their children's needs/abilities. I also learned more about how complex parents' concerns were. Although there are things that all families appeared to need to some extent (e.g., respite), each family had their own individualized strengths, weaknesses, and

outcomes. I struggled to make sense of the complexity both during my placement and in my analysis. I often looked to the biopsychosocial model to help me make meaning of parents' lives.

The clinical theoretical background that I adhere to is the called the biopsychosocial model, and it has become part of my worldview. This model posits that an individual's biology, their thoughts/emotions, and their social environment are combined to impact an individual's behaviours and life outcomes (Borrell-Carrio, Suchman, & Epstein, 2004). During my thesis analysis I tried to keep these factors and their influences in mind, to try and provide the most objective and multifaceted view of parents' lives as possible.

My career experience has focused on the often unmet needs of parents raising children with developmental disabilities. My perspective is that the negative aspects of raising children with developmental disabilities is important and that parents require validation for those experiences. However, through the analysis of the manuscripts, my perspective has shifted to value a strengths based approach as well. Many parents discussed how helpful it was to discuss what works in support groups, rather than focusing on the negative. The call for a balance in research focus of what is going well for parents and what is needed, was the inspiration for the manuscript regarding supports for families with developmental disabilities. My work has inspired me to endeavour to remain in the field of developmental disabilities upon graduation, either clinically or in a research related capacity.

1.8.1 Navigating the researcher-participant relationship. An important part of reflexivity is to acknowledge how the researcher relates to the participant, and how the resulting relationship can affect participant responses (Hsiung, 2010). This research project was my first experience with interviewing in a research capacity. I did have experience with intake interviews in a clinical capacity, so I had some experience with attempting to control influential factors that

could impact a participant's responses during an interview such as my facial expressions, and maintaining an awareness of personal impressions or biases about the participants. However, I found interviewing in the role of a researcher, rather than a clinician, to be challenging.

I struggled most with the instinct to 'help' struggling parents. As a researcher, my role is to allow the participants to talk freely and choose the direction of the conversation. Although I had certain topics in mind when interviewing, the participant chose what and how much to divulge. I found it extremely difficult to withhold my clinical skillset during interviews, particularly when participants only seemed to require some psychoeducation or emotional validation. Learning to let go of the instinct to help or intervene, and to let the participant talk were the first skills I learned.

Another issue that arose was participants asking me about my personal life and experiences. In the interest of building rapport, I decided ahead of time to respond to appropriate questions in an effort to reduce the hierarchical researcher-participant dynamic (Dickson-Swift, James, Kippen, & Liamputtong, 2007). I was careful to keep my answers to a minimum and did not volunteer any personal information during the interviews, so as to minimize my influence on participants' answers.

I was also encouraged by Dr. Watson to keep notes of my emotions, my perception of the participant's emotions, and the content of each interview at its conclusion. When listening to the interviews via the recording, I made notes if I thought there were differences in how I was asking the questions (e.g., too encouraging) or the tone of my voice. In the interest of transparency, I made notes of why I chose or eliminated certain themes, and often questioned myself about why I chose to use the quotes I used.

I am grateful to the families I had the privilege to work with and that they were willing to accept the vulnerability of sharing their tribulations and triumphs with me. In the interest of giving back to the relationships my colleagues and I have established, as part of my knowledge translation efforts I will be providing them with a copy of the journal articles they contributed to. It is important that they receive a return on their efforts. Further information regarding the efforts undertaken to promote knowledge translation can be found in the Knowledge Translation section in Chapter 4 of this thesis.

1.9 Methodology

The current mixed methods study (Teddlie & Tashakkori, 2009) was conducted to expand and enhance results from a larger project, also informed by the FAAR model (Patterson, 1988), that focuses on the array of experiences related to raising a child with a developmental disability. Mixed methods can provide meaning to quantitative measures through participant interviews, and can provide the opportunity to compare and contrast qualitative and quantitative results (i.e., triangulation; Guest, MacQueen, & Namey, 2012). The rationale for mixed methods is that analyzing and merging qualitative and quantitative data can provide a greater degree of trustworthiness, breadth, and depth of topic examination than either method can when analyzed alone (Creswell, 2014; Guest et al., 2012; Johnson & Onwuegbuzie, 2009; Teddlie & Tashakkori, 2009).

For the purpose of this study, a convergent parallel mixed method design was used (Creswell, 2014). A convergent parallel design entails separate analysis of the qualitative and quantitative results, followed by a comparison between the two (Creswell, 2014). The qualitative data were analyzed first, so as not to influence the creation of themes with the quantitative findings. It should be noted that each paper had its' own respective method of qualitative

analysis (i.e., Interpretative Phenomenological Analysis or Thematic Analysis) due to differing research questions. Further information pertaining to the analysis can be found in the Qualitative Interviews section.

The larger study was also a mixed methods project. Qualitative data was obtained through semi-structured interviews, and quantitative measures were obtained using six psychometric questionnaires. The six questionnaires were mailed to participants along with a prepaid envelope, and were returned after completion. A demographic questionnaire was also included in the mailed package that included standard demographic information such as age, income, and number of children in the family with a disability. However, the focus of this thesis pertains to adopted adults with FASD and families of children with FASD or ASD. Results from the larger project beyond the scope of this study are presented elsewhere (Watson, Coons, et al., 2013; Watson, Hayes, et al., 2013). Ethics approval for this research was obtained from the Laurentian University Research Ethics Board (See Appendix A).

1.9.1 Participants. Families were accessed through several Children's Aid Society locations as well as through disability support organizations (e.g., FASD Stakeholders of Ontario), adoption support organizations (e.g., Adopt Ontario), and support groups (e.g. FASworld Family FASD Support Group) across Ontario, Canada. The aforementioned organizations were contacted via email and participants were asked to contact the lead researchers should they wish to participate. Respondent driven sampling was also used, whereby the lead researcher contacted known individuals for assistance in accessing families interested in participating in the study (Salganik & Heckathorn, 2004).

A total of 26 families participated in the studies for this thesis; eighteen families had children with FASD, and 8 were families of children with ASD. Forty-one participants

completed both of the interview and questionnaire components. Three participants completed only the quantitative component. Participants included adoptive parents, step parents, foster parents, and biological parents. To qualify for participation, parents must have had at least one child with FASD or ASD. The number of children with disabilities in the family ranged from 1 to 4. The children's ages ranged from 3 to 37. Parents' names were replaced with pseudonyms to protect their identity. Table 1 below shows a summary of additional population demographics.

Table 1

Participant Demographic Characteristics

Demographic Characteristics	
Characteristics of mothers (*n*)	29
Average age (*SD*)	50 (12.7)
Age range	28-71
Relation to child with disability	
Biological[a] (*n*)	8
Step-parent (*n*)	1
Adoptive (*n*)	19
Foster (*n*)	1
Married (%)	24
Characteristics of fathers (*n*)	12
Average age (*SD*)	46
Age range	29-73
Relation to child with disability	
Biological[b] (*n*)	8
Step-parent (*n*)	1
Adoptive (*n*)	8
Foster (*n*)	-
Married (%)	100
Characteristics of children (*n*)	62
Gender (% female)	33.9
Average age (*SD*)	14.8 (10)

Note: [a] = biological relationship to child including grandmother, [b] = biological relationship to child including grandfather

1.9.2 Qualitative interviews. Semi structured interviews, informed by a basic interpretive approach, were conducted with participants (Merriam, 2002). The interviews were designed as part of the larger project (Watson, Hayes, et al., 2013; Watson, 2008a, 2008b), consisted of 22 questions, and prompts were used if deemed necessary (See Appendix B for complete interview guide). All questions were open ended to minimize the researcher's influence on participants' answers. An example of an open ended question is, "Please describe a typical day in your home", and the associated prompt is, "Can you please run me through your morning routine?"

As part of a larger ongoing study, the interviews and questionnaires were also administered by three other researchers, including the lead researcher, and two other graduate students. I personally contributed 8 complete interviews and corresponding batteries of questionnaires to the larger project. The time and location of the in-person interviews were chosen by participants (e.g., lunch at a coffee shop), or were conducted over the phone. The questionnaires were completed and mailed back to the principal researcher. The questionnaires and interviews were analyzed separately, and therefore interviews were conducted irrespective of the questionnaires' arrival. The duration of each interview varied with each participant, and ranged approximately from 30 minutes to two hours. Parents were contacted via email when necessary for any follow up questions that arose during the analysis.

Each study employed a different method for analysis. The first study employed Interpretative Phenomenological Analysis (IPA), and the second study utilized Thematic Analysis. Different analysis types were used due to differing research questions. The first study focused on participants' experiences, which is characteristic of IPA analysis. In contrast, the second study had a narrower scope of focus and examined the specific supports parents required,

resulting in the use of Thematic Analysis. Further information regarding the methods used for each study's respective interview analysis is provided in greater detail within each manuscript.

1.9.3 Questionnaires. Three questionnaires were chosen from the 6 psychometric tests administered as part of the greater project: the Questionnaire on Resources and Stress-Friedrich's Version (QRS-F), the Family Resource Scale (FRS), and the Family Crisis Oriented Personal Evaluation Scales (F-COPES) (Dunst & Leet, 1987; Friedrich, Greenberg, & Crnic, 1983; McCubbin, Olson, & Larsen, 1981). They were chosen based on their applicability to the research questions. All three questionnaires were analysed using descriptive statistics, including averages, standard deviations, and frequencies. The questionnaires are either categorical (FRS) or ordinal (FRS, F-COPES), therefore descriptive statistics are most appropriate. Further details on each questionnaire, the rationale for their inclusion and analyses for each respective study can be found in the subsequent manuscript chapters.

1.9.4 Mixing the data. The questionnaire and interview data were presented in an embedded format, with a primary focus on the qualitative data. The interview data were chosen as the primary sources of analysis due to the first research question, which seeks to understand participants' lived experiences. The interviews were comprehensive and provided rich descriptions of the participants' lives. The quantitative data is presented in an embedded format within the presentation of qualitative themes because the quantitative data's primary function is to provide additional theme evidence (Creswell, 2014). The purpose of embedded mixed data is to establish triangulation, whereby multiple data sources are combined to provide additional support (Creswell, 2014; Guest et al., 2012). For example, a theme is presented with a corresponding questionnaire item as further support either in text or table format.

1.10 Conclusion and Overview of Subsequent Chapters

This manuscript based thesis, informed by the FAAR model, examines supports families require to facilitate parents' transition from the adjustment phase to the adaptation phase, as well as any hindrances to that process. Following the larger, ongoing project, both studies employed mixed methods using a basic interpretive approach (Merriam, 2002). Questionnaire data was analyzed using descriptive statistics, and the semi structured interviews were analyzed using either Interpretative Phenomenological Analysis or Thematic Analysis (Braun & Clarke, 2006; Guest et al., 2012; Smith, Flowers, & Larkin, 2009). Using both qualitative and quantitative data sources provides a more complete picture of parents' experiences than either source of data could alone (Johnson & Onwuegbuzie, 2009; Teddlie & Tashakkori, 2009).

The first paper includes a mixed methods analysis regarding the experiences of families of adopted adult children with FASD, and parents' needs as they endeavoured to adapt to their children's transition into adulthood. Findings suggest that parents' demands were outweighing their capabilities. Parents required a variety of supports for their children including semi independent housing, work assistance, financial assistance, and encountered general difficulty accessing adult formal services for their children. Extending the current research to other family types such as birth families would be beneficial as birth parents may have FASD themselves, meaning they would also require adult FASD services (Denys, Rasmussen, & Henneveld, 2011).

The second paper included is also a mixed methods analysis, and examines specific supports (i.e., formal and informal services) that families of children with FASD and ASD required for their children, specifically during the middle childhood stage of development. Parents highlighted the importance of obtaining a formal diagnosis for service access, requested extended child supervision services, discussed extensive waiting lists for formal supports, and

called for further education of professionals. Conversely, parents reported utilizing services like support groups and advocating on behalf of their children as strengths that facilitated adaptation. Implications for receiving disability related services early in life are discussed.

Following the two papers, the fourth and final chapter provides a summary of the studies with concluding remarks and discussion of the larger project. Considerations and future research directions are also provided. Finally, implications and efforts towards knowledge translation are described.

“Well Where’s He Supposed to Live?”: Experiences of Adoptive Parents of Adult Children with FASD in Ontario

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Abstract

The purpose of this paper is to gain a better understanding of the experiences of adoptive parents of adult adoptees with Fetal Alcohol Spectrum Disorder (FASD), and to examine their needs as they are adapting to their children's transition into adulthood. Twenty parents from Ontario completed the Questionnaire on Resources and Stress- Friedrich's Version (QRS-F), as well as a semi structured interview informed by the FAAR model. Using Interpretative Phenomenological Analysis (IPA), three major themes were identified from the interviews: housing and transition into adult housing, managing money/finances, and individual characteristics. Each theme is discussed in detail. The QRS-F was analyzed using descriptive statistics and results indicate that parents were, on average, experiencing moderate levels of stress. The findings suggest that those parents required additional resources such as adult housing to facilitate adaptation and minimize perceived parental stress. Research considerations and future directions for FASD investigation are discussed.

"Well where's he supposed to live?":

Experiences of Adoptive Parents of Adult Children with FASD in Ontario

Fetal Alcohol Spectrum Disorder (FASD) in an umbrella term that encompasses the following diagnostic categories, all of which are caused by in utero exposure of an individual to alcohol (ethanol): Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), and Alcohol-Related Neurodevelopmental Disorder (ARND; Koren & Nulman, 2014; Rasmussen & Bisanz, 2009; Saddok & Saddok, 2007; Streissguth et al., 2004). The diagnostic process for FASD is constantly evolving, and often requires a multidisciplinary team to make a formal diagnosis (Chudley, Kilgour, Cranston, & Edwards, 2007; Pei & Rinaldi, 2004). The changes in diagnostic criteria can act as a barrier when estimating the prevalence of FASD within a given population (Chudley et al., 2007).

Currently the most commonly cited estimate of the prevalence of individuals with FASD in Canada is 9.1 per 1000 live births, or approximately 1% of the population (Canada FASD Research Network, 2015; Health Canada, 2006). Due to lifelong challenges and co-morbidities, the annual cost of treating and caring for individuals with FASD in Canada has been estimated to be approximately 7.6 billion dollars (Thanh & Jonsson, 2009). Individuals in care with FASD often make use of formal services throughout their lifespans, and many are unable to achieve self-sufficiency by the age of 18 (James Williams, Dubovsky, & Merritt, 2011).

Individuals within the child care system (e.g., foster care, child welfare system) are particularly at risk of an FASD diagnosis as they are more likely to be exposed to prenatal alcohol and other unfavourable conditions (Popova, Lange, Burd, & Rehm, 2014). In 2013-2014, there were 977 finalized adoptions (Ontario Association of Children's Aid Societies, n.d.). In 2014 there were an estimated 18,564 children in care in Ontario, and of those children, there

were an estimated 612 to 2,096 (approximately 3-11%) individuals with FASD (Popova et al., 2014). Those adoptees are at risk for primary and secondary disabilities.

Primary disabilities are caused by underlying brain or central nervous system irregularities and include symptoms such as cognitive impairments, negative changes in adaptive functioning, memory deficits, and language comprehension (Malbin, Boulding, & Brooks, 2010; Streissguth & Kanter, 1997). Primary disabilities can cause individuals with FASD to be predisposed to secondary disabilities, which tend to occur later in life (Streissguth et al., 2004). Secondary disabilities include trouble with the law, alcohol/drug problems, inappropriate sexual behaviour, dependent living, and problems with employment (Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008; Streissguth et al., 2004; Streissguth & Kanter, 1997).

Individuals with FASD often contend with primary and secondary disabilities across their lifespan, but there are surprisingly few longitudinal studies including adults with FASD (Connor, Sampson, Streissguth, 2007; Streissguth, Bookstein, & Barr, 2006; Connor & Streissguth, 1996; Streissguth et al., 2004). Primary disabilities are especially problematic for adult individuals with FASD because skills such as problem solving, abstract reasoning, and functioning memory are required in any given workplace and are required for managing personal appointments or finances; deficits in these areas mean that individuals with FASD may require lifelong intervention for these factors (Chudley et al., 2005; Connor et al., 2006; Connor & Streissguth, 1996; Streissguth & Kanter, 1997).

Due to the lifelong challenges encountered by individuals with FASD, parents may be assisting their children with the aforementioned tasks, when children of typical development are able to complete them independently. Research shows that the majority of adults with FASD reside in their parents' household, with up to 80% living in the home of their primary caregiver

(Clark et al., 2008; Streissguth & Kanter, 1997). Studies show that being raised in, or living for an extended period of time in a stable home environment can act as one factor that reduces the risk of secondary disabilities (Streissguth & Kanter, 1997; Streissguth et al., 2004). Living with a caregiver has also been found to have the maximum impact on improving the inclusion of adults with FASD into the larger community (Clark et al., 2008).

Living within the home of a caregiver as an adult is typical of a life stage called emergent adulthood, that includes individuals who are 18 to 25 years old (Arnett, 2000; Bynner, 2005). Young adults in this phase of life have a tendency to exhibit a pattern of moving in and out of their parents' home, and do not view that movement pattern as a negative reflection upon their adult status (Arnett, 2000). Emerging adults also typically believe there are three characteristics an individual needs to demonstrate before they can be considered a normative adult: the ability to accept responsibility, to make independent decisions, and to become financially independent (Arnett, 2000). Emerging adulthood is best described as a stage of change, where individuals are forming their identities as adults (Arnett, 2000).

The transition from emergent adulthood to adulthood for individuals with disabilities is a time of increased uncertainties and challenges (Arnett, 2000; Kim & Turnbull, 2004). There is a shift in parents' goals for their children, from a focus on education to an emphasis on employment, independent living, and social relationships (Henninger & Taylor, 2014). There is also a shift from children's services into adult services. Parents of children with FASD face unique challenges procuring adult services due to their children's capacity to over represent their abilities (e.g., decision making) in comparison to other individuals with disabilities (Chudley et al., 2007). A child's transition into adulthood can result in a change in the family's core functions with regards to the required economic support, and nurturance (Patterson, 2002). A

change in core family functioning is considered a crisis within family adaptation literature, and can result in significant perceived parental stress (Patterson, 1988; Watson, Coons, & Hayes, 2013). One theoretical framework examining family adaptation capabilities is the Family Adjustment and Adaptation Response (FAAR) Model (Patterson & Garwick, 1994b, 1998; Patterson, 1988).

The FAAR Model

The FAAR model entails three systems that facilitate adaption: the individual, the family, and the community (Patterson & Garwick, 1994b, 1998; Patterson, 1988). In this model the family, as a social system, strives to maintain good family functioning (homeostasis) by employing coping skills and resources (consisting of the aforementioned three systems) to mitigate any negative effects from stressors or strains (Patterson, 1988).

There are two phases to the FAAR model that are divided by a crisis event (Patterson & Garwick, 1994b; Patterson, 1988). The first phase is the adjustment phase, which can be characterized as a stable period in family functioning when families are generally able to meet the demands with their existing capabilities. Only minor changes are made in the family dynamics. For example, a child may begin attending college while living at home, but the child's role within the family context remains essentially the same.

The adjustment phase is interrupted with a crisis, or in other words, an event that upsets the equilibrium of the family social system (Patterson, 1988). It should be noted that a crisis does not always imply a negative event, but an event that changes the pattern of family functioning or communication. For example, an adult child moving into an independent living situation is considered a positive event, but is considered a 'crisis' in the FAAR model due to the required shift in family roles and needs. The crisis causes a state of disequilibrium when the demands

surpass the family's existing resources and coping abilities and as a result, a family's capabilities must be strengthened.

After a crisis occurs, families move into the second phase of the FAAR model called the adaptation phase. During the adaptation phase, families overcome the new demands placed upon the family by attempting to use their range of capabilities. In order to equalize the demand/capability imbalance, the family must make changes to enhance their capabilities. For example, adults can take life skills courses to increase their self-sufficiency in daily tasks.

A stressor can be defined as a transition or event that can potentially produce a change in the family social system (e.g., change in the family's boundaries, goals, or values; McCubbin & Patterson, 1983). A strain emerges insidiously into the family and has no discrete onset. Strains emerge when there is an inability to completely resolve a stressor, or when there is a dissonance between family members' role expectations (Patterson, 1988). Strains can also develop when a maladaptive pattern of behaviour originally intended to help maintain family balance begins to negatively affect the family (Patterson, 1988).

According to the FAAR model, families are in a constant fluctuation between the adjustment and adaptation phases. Problems emerge when families fall into the poor end of the adaptation continuum and are unable to cope (e.g., perceived parental stress; Glidden, Billings, & Jobe, 2006). Families who experience difficulty with adaptation often require additional support (e.g., formal and informal supports) to bolster the coping skills and resources they already possess as a family system (Fontenot, 2007; Jones & Passey, 2004).

There are support services available to adults with developmental disabilities, including FASD, in Ontario. Services like Ontario Works help individuals who are in financial need acquire a working position (Ontario Ministry of Community and Social Services, 2012).

Additionally individuals may apply to the Ontario Disability Support Program (ODSP) for financial assistance for basic needs, and to apply for medical benefits (Ontario Ministry of Community and Social Services, 2015). To gain access to the ODSP, an individual must first qualify as an individual with a disability.

To the author's knowledge there is no existing published research regarding the experiences of adoptive parents of children with FASD during their children's adult stage of development. Research shows that the majority of adult individuals with FASD are residing within their parents' homes however, little is known about the needs of parents at this stage of their children's lives. Adulthood poses new and unique requirements from childhood, such as transition into adult services. Parents who lack required adult supports fear negative outcomes for their children's futures and perceive this to be a source of stress. This is an indication that they are struggling to adapt to the adult stage of their children's lives (James Williams et al., 2011; Michaud & Temple, 2013; Watson, Coons, et al., 2013; Watson, Hayes, Coons, & Radford-Paz, 2013). Parents who are having difficulty with adapting to their children's transition to adulthood may require additional services. Adoptive parents' needs are important as parents can act as a protective factor for the life outcomes of their adoptees (Streissguth et al., 2004). The purpose of the present study is to identify the experiences of adoptive parents of adult adoptees with FASD, and to examine their needs as they are adapting to their children's transition into adulthood.

Methodology and Methods

The current study employed a mixed methods research design, and is part of a larger project regarding families of children with developmental disabilities (Watson, Coons, et al., 2013; Watson, Hayes, et al., 2013). Semi structured interviews were conducted and the

Questionnaire on Resources and Stress- Friedrich's Version (QRS-F) was administered (Friedrich, Greenberg, & Crnic, 1983). The choice of the interview questions and the QRS-F was informed by the FAAR model (Patterson & Garwick, 1998), as well as previous research regarding families of children with disabilities (Watson, 2008).

Mixed Methods Research

Mixed method research designs involve the collection and integration of qualitative and quantitative data in a single research study (Creswell, 2014; Teddlie & Tashakkori, 2009). The rationale for mixed methods is that the combination of qualitative and quantitative data can provide a more valid, and a more in depth analysis of parents' adaptation, than each type of data can achieve when analyzed alone (Creswell, 2014; Guest, MacQueen, & Namey, 2012; Teddlie & Tashakkori, 2009). Data were analyzed using a convergent parallel design, whereby each type of data was analyzed separately, and then were compared and contrasted with each other (Creswell, 2014). The interviews were analyzed and the descriptive statistics for the QRS-F were calculated separately, followed by an integration of the results.

Participant Recruitment and Inclusion Criteria

In order to participate, parents had to have at least one adopted child with FASD, who has reached the legal age of adulthood (i.e., 18 years). The adoption of the child had to occur before adulthood. Adult adoptees ranged in age from 19 to 37, with a mean age of 27.35. Adoptive parents were recruited through FASD support organizations located across Ontario, Canada. Emails were sent to 28 agencies, who then asked participants to contact the lead researcher if they wished to participate in the study. Respondent driven sampling was also used, whereby the lead researcher contacted known individuals for assistance in accessing families interested in participating in the study (Salganik & Heckathorn, 2004).

Qualitative Interviews

Semi structured interviews were conducted with adoptive parents of adult children with FASD, following the basic interpretative approach (Merriam, 2002), an inductive strategy used in an effort to understand how participants make meaning of a given situation. The interviews consisted of 22 open ended questions, and prompts were used if deemed necessary. An example question is, "Please describe a typical day in your home." The following prompt associated with that question was used when required, "Can you please run me through your morning routine?" No close ended questions were asked to prevent leading the participants in their answers. The interviews were conducted by the lead researcher of the present study, in addition to two other researchers who were part of the larger family project. Interviews were conducted at a time and place convenient for participants (e.g., coffee shops or family homes). Parents were interviewed separately or together, based on their preference. Follow up questions were asked via email or telephone if questions arose during the qualitative analysis.

Qualitative Data Analysis

All interviews were audio recorded and transcribed verbatim. Researchers reviewed the transcripts several times, whilst making notes in the margins. Using Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009), the transcripts were reviewed again in order to transform the notes into specific themes, or codes, which were clearly defined (Smith et al., 2009). Searching for repetition in answers is considered one of the most common methods for defining themes (Guest et al., 2012; Ryan & Bernard, 2003). Afterwards a search was conducted across the emergent themes to then cluster them into groups, thereby further reducing the data, providing them with additional meaning (Smith et al., 2009). The

cluster of themes were then given labels derived from quotations from the interviews to promote theme validity (Guest et al., 2012).

In addition to employing direct quotes, attempts were made to make the analytic process as transparent and valid as possible. An audit trail was maintained including the development of the definition of themes, the exclusionary theme criteria, and quotes associated with each theme. Member checking was also conducted whereby participants were given the opportunity to provide feedback on the validity of the themes via email. Finally, interrater reliability was established through the discussion of findings with other researchers of the larger project.

Questionnaire

The QRS-F was provided to participants for completion either in person or via mail (Friedrich et al., 1983). The QRS-F measures aspects of perceived stress as experienced by families with a child with a disability. The QRS-F has been used with parents of children with a variety of developmental disabilities, including parents of adult children (Ben-Zur, Duvdevany, & Lury, 2005; Friedrich et al., 1983; Honey, Hastings, & McConachie, 2005; Walker, Van Slyke, & Newbrough, 1992). Previous research has demonstrated internal consistency and reliability, with a reliability coefficient of 0.95 (Honey et al., 2005; Vijesh & Sukumaran, 2007). The QRS-F contains 52 items assessing four areas of stress related to: parent and family problems, parental pessimism about their child's future, child characteristics, and the physical incapacity of the child. The answers are provided in a true or false format. Higher scores indicate higher levels of perceived stress and lower scores vice versa. A score ranging from 0-17 indicates a mild level of perceived parental stress, a score of 18-34 indicates a moderate level, and a score of 35-52 indicates a severe stress (Ben-Zur et al., 2005; Friedrich et al., 1983). An example item is, "The family does as many things together now as we ever did."

Quantitative Analysis

Due to the exploratory nature and small sample size of the present study, descriptive statistics such as percentages were calculated. The questionnaire data were analyzed separately from the interviews after the IPA was completed to minimize any researcher bias during interview analysis. The quantitative data is presented in an embedded format within the qualitative data as its function is to provide additional theme evidence (Creswell, 2014). For example, a theme is presented with a corresponding questionnaire item as further support. Triangulation is the method of comparing research evidence to provide additional support (Creswell, 2014).

Results

Twenty parents participated in the study, representing 12 adoptive families. Parents ranged in age from 52 to 73, with a mean age of 61.19. The data were gathered as part of a larger family project, but for the purpose of this study, only the data pertaining to the parents of adopted children data were examined. See Table 1 for a summary of additional participant demographics.

Table 1

Participant Demographics

Parent Characteristic	*n*	%
Gender		
Male	5	35
Female	15	75
Current Marital Status		
Married	16	80
Divorced	2	10
Single	2	10
Family Type		
Adoptive Mother	15	75
Adoptive Father	4	20
Step Father	1	5
Number of Children with FASD		
1	17	85
2	3	15

All parents identified stressors that acted as barriers to planning for the future for both the child and their parents. The transition of a child into adulthood can create a crisis within the family system (see section on the FAAR model), and there are only limited resources available to provide support (e.g., housing) in Ontario. Through the use of IPA, three major themes emerged from the interviews (Smith et al., 2009). These themes included the transition of the child into adult housing, children's inabilities to manage finances, and difficulties associated with individual characteristics (e.g., risky behaviours). Each of the themes is presented in detail, with integrated quantitative and qualitative supporting evidence. Pseudonyms were used to protect the identity of participants. The questionnaire data were confirmatory of each theme.

Parents reported on the QRS-F that they are, on average, experiencing moderate levels of total perceived stress (M= 24.6, SD= 9.5). Parents' total stress scores ranged from 10 (mild) to 36 (severe). Unfortunately, only 12 parents' scores were calculated as eight of the questionnaires were missing scores for several items. The questionnaires identified that parents were

experiencing stress, and the interviews provided insight as to why or why not parents felt they were stressed. The following themes are examples of issues associated with parents' elevated levels of perceived stress.

Housing and Transition into Adult Housing

All parents reported a strong desire to acquire or maintain a stable living environment for their child. Two subthemes emerged. Parents expressed that the problem of a lack of appropriate housing services is compounded by their children's unwillingness to change their living situation or daily routines. The adult children maintained a heavy reliance upon their parents and were unwilling to change.

"Cause he's gunna stay here, he's not leaving": Adoptee difficulty managing change. Parents discussed a propensity for their children to believe that their home life will remain the same, and that their parents will always be there to support them. Change of any kind was reported by parents to be perceived as a great source of anxiety for their children. Melissa, who has a 37-year-old son with FAS, discussed her son's lifelong aversion to change, "Even when he was a kid, a change of clothes, a change of driving route in the car, any change has been really difficult for him." This distaste for change can be problematic for adult children who desire independence, but are too fearful to leave the home. Gabrielle, mother of an adopted daughter thought to have FASD, explained that, "It was like she couldn't let go of me. But she didn't want to be home and abide by the rules." The struggle of adult children to maintain an independent lifestyle and make their own rules, whilst living dependently was reported to be a source of frustration for everyone involved. Sharon, a mother of two boys with FASD, described her 19-year-old son's capacity to follow household rules, "It's like he's always a child but he

doesn't want to be a child. It's like we're stuck at two." However not all children remained in the home permanently.

In the event that the adult children had the capacity to make the foray into a life independent from their parents, they rarely remained there permanently. The adult children often returned to the home as a sort of safety net. Parents reported a pattern of child movement in and out of the home and/or frequently changing housing situations. They described their child's living situation as a 'revolving door.' Adoptive parents Bailey and Trevor described their adult son's attempts to leave the home, "The stress was unbelievable. No, he didn't wanna come home. As far as he was concerned he was doing fine. And then he was back. And then he went out. And then he was back."

Parents reported that the indecisive nature of their children's lives was a great source of anxiety. All parents reported having 'no idea' what their children's futures will hold. Beverly and Drew commented that, "we'll always be worried about him." A sense of apprehension about the future was also reflected in results from the QRS-F, where 100% of respondents responded true to the item, "I often worry about what will happen to ____ when I no longer can take care of him/her". Parents reported attempting to assuage their worry by assisting their child in the search for housing and/or other services.

Parents' efforts to assist with their child's transition out of the home (e.g., providing an alternative living situation or enforcing follow through for a job) were often thwarted by their children, as parents no longer held legal power for their children. Parents lose legal guardianship when their child turns 18, which is a fact that many adult children took advantage of for the improvement of their personal freedom. For example, parents lost their ability to enforce rules. The children were reported to be aware of their newfound rights as adults, and were resistant to

upholding household rules or chores. For example, parents Stacey and Ivan described a typical interaction with their son regarding rules to be followed in the home, "he always tells us he's legal now, he can do whatever he wants." Although tension between growing children and their parents is a normative experience, it became clear to parents that their children needed to move on to their own homes. Parents report not knowing where to send their children to live, even if their adult child was willing to move.

"He's too good for this, but not bad enough for that… He shouldn't be living there": Lack of appropriate housing services. Parents discussed how the lack of appropriate housing left their adult children with few residence choices available to them. Sharon, an adoptive mother, asked "Is it better that your kid's in jail or out on the street?" Parents discussed a need for more support for their child than standard subsidized housing. Joseph discussed his daughter's disappointing use of government funded housing, stating that it, "gave her cheap rent. It doesn't give her support."

Parents referred to a need for a structured living environment that can foster independence, while simultaneously ensuring that their children are supported (i.e., direct supervision). Adoptees required someone to say "these are the things you are going to do today". Parents reported that their children required special help with specific things such as taking medication, personal hygiene, maintaining an appropriate diet, and reminders to complete tasks (e.g., go to work). Ivan described what they felt would be the perfect living experience for his children:

> A built in community housing project or whatever that totally understands the problem, lets the kid be independent as an adult, gives them some rules and responsibilities, but yet is there saying uh-uh, shower day is today, or you're not going out the door till you've brushed your teeth.

Six families (50%) reported that they were able to procure housing outside the home for their children, paid for, at least in part, through ODSP. Five families reported having children living in apartments, and one in residence. Their children did not achieve full independence in their new environments, and often looked to home for additional support. For example, Stephanie and Chad reported having their adopted son live at their home on the weekends. Parents reported helping individuals who lived outside the home with finances, as well as finding and/or maintaining their jobs (see subsequent sections). Furthermore, parents stated that housing of any kind can be exceedingly expensive, and those who do not qualify for social services (e.g., ODSP) required extra financial support.

Managing Money/Finances

Parents described a heavy cost associated with procuring services (e.g., housing) for their children. The high cost can be mitigated through Ontario financial assistance programs like ODSP, if the adult children manage to qualify. In the event that the adoptees do attain financial assistance, parents report that their children were often not able to effectively manage those resources. Additionally, parents recounted how acceptance of financial aid, although monetarily helpful, can reduce their children's motivation to adhere to a structured lifestyle (e.g., maintain a job). Two sub-themes help provide a detailed understanding of this theme.

"There was always a reason why she wasn't eligible": Difficulty accessing adult services. It can be difficult for adult children to meet the qualifying criteria for funding programs, such as ODSP, because the features of their FASD may not present as severe enough for program acceptance. Often adoptees were considered to have IQs that were too high to qualify for services. Stefanie recalls being turned down for a funding opportunity because her son, "was one [IQ] point above" the cut off for the qualifying level of IQ. Ivan encountered the same issue when applying for services and described why, "he's not dumb enough, his IQ's too high so you can't [access services]". The aforementioned children had a formal diagnosis of FASD, and it can be even more difficult for those who do not.

A formal diagnosis of FASD is often required to obtain funding. It can be particularly difficult for adult children to obtain a professionally recognized diagnosis of FASD, due to issues like missing biological family information, which places them at a further disadvantage for services. Chad described his experience with one doctor who said his son, "doesn't look FAS and unless you can get a history we can't [diagnose]." Jocelyn also noted the difficulty of attaining a diagnosis for older individuals stating that, "these older ones are just hanging around without any formal diagnosis, it's hard for them to get help." Jocelyn further discussed how services like ODSP are becoming increasingly reliant upon diagnosis for service qualification. Upon an eventual professionally recognized diagnosis, Chad almost immediately received a 'pension' for his son; however, even after the qualification of services was granted, parents reported that it was a lengthy process to actually acquire the services. Julie described her experience with the availability of services in Ontario, "Services kind of dry up for children in that 16 and above. Certainly 18 and above."

Parents also reported that the few existing services available like respite care, were overburdened with too many individuals looking for help, resulting in extensive waiting lists. Mandy recalled being told that her desired housing service was chronically full. She explained that, "we're on the list but we're not making our way up the list." The few available services were also expensive. Julie recounts how fortunate she was to have a good income. She discussed that the supports she was able to find were, "not available to people without lots of money." In addition to parents' struggles with financial strain, their adult children experienced difficulties with procuring and managing their finances independently.

"**If you gave the kid $100, it would be gone": Adult child difficulty procuring and managing finances.** Parents of adult children who have obtained financial aid like ODSP referred to it as "a double edged sword" because any income adoptees made while working was deducted from their automatic income. It was more cost effective for their children to subsist on ODSP alone than to work through initiatives like Ontario Works. Stacey discusses how ODSP created a 'catch 22' for her adopted son:

> If he does get a part time job, that's partially deducted from his ODSP, which is reasonable but what's the incentive of him getting up and going out to do anything. On the other hand, if he wasn't getting ODSP we have to be, um, financially responsible for him. Whether or not he'd actually go out and look for work, we don't know.

Parents also reported that not only are their children not motivated to work for additional money, but they also have a propensity to spend any money they had access too. Adoptees had difficulty planning ahead and sticking to a budget. Parents described their children's notions about budgeting, and how those strategies were hastily abandoned when they were granted access to money. For example, Kaylee described how her son always had "wonderful plans" for

the use of his money but that “the first thing he and his roommate do is go out and buy beer.” A propensity for excessive expenditure is problematic for children who are limited financially, and who were considered by parents Beverly and Drew to be classified as the “working poor”. All parents agreed that their children needed additional aid managing finances at, at least one point in their lives.

In times of financial need, parents reported stepping in to financially assist their children. Parents reported that although they had enough funds to support their own necessities, they worried on behalf of their children. According to the QRS-F, 80% of participants reported that they almost always had an adequate amount of money to support their family. Parents also reported that although their immediate needs were met, the additional financial burden of supporting their child has, at least at one point in time, caused them to forego ‘extra activities’. Fifty-two percent of parents reported that other members of the family have had to go without things because of ____.

Parents reported attempting to intercede to help their children with financial tasks such as putting money away to save, paying the bills, or keeping track of bank accounts. For example, Stephanie described her process of ensuring her son’s rent is paid and “letting so much money in his account to use”. She does not believe he would ever pay rent on his own. Parental financial intervention can be difficult if the child resists, as parents do not have legal control over their adult children (see section on Adoptee Difficulty Managing Change). Parents also described the tendency of their children to give money to others amongst a host of other risky behaviours that are barriers to the maintenance of a normative adult life. The individual behaviours and characteristics of adult adoptees varied; however, there were two patterns of behaviours that emerged from the interviews.

Individual Characteristics

Parents described two behaviour tendencies exhibited by their children, which made it difficult to obtain or maintain employment, further contributing to their financial need. Adoptees were reported to be easily taken advantage of by others, to have a predisposition to use alcohol or drugs, and to have had involvement with the criminal justice system. The aforementioned adult child behaviours, in addition to features inherent to FASD (e.g., difficulty sustaining attention), further promote job instability.

"The level of risks they take are huge": Risky behaviours. Parents described how their children were easily led astray by antisocial individuals. Specifically, they were described as prone to giving away their money, or to following others in engaging in criminal activity. Parents described their children as potentially being the perfect gang members, or how they could easily get into trouble with the law due to their compliant behaviours, particularly when money was involved. Trevor described his son's relationships with others, "It never clued in to him that the only time he really had friends, close friends, was when he had a pocket full of money." Beverly and Drew reported that their son as "always been influenced by other people to a greater extent than we felt was healthy." John described his son as "mixing with the wrong crowds". Furthermore, parents reported that their children's desires to fit in and follow others were chronic. Emily, an adoptive mother, described her daughter, 'getting hurt over and over again and [she] just doesn't get it'. The propensity to be easily led by others can lead to engagement in criminal activity. For example, Sharon describes her son's behaviours while living on the street:

> He will go and put himself in extreme dependent situations, very exploitive situations. Right, when he's living on the street et cetera with, you know, with people who exploit him for selling drugs, et cetera.

In addition to the risk of criminal activity, parents also reported alcohol use, running away, a risk of self-harm, and psychological disorders. Stefanie described one instance in which police were searching for her missing son, “he would have a knife and rope with him and you never knew whether his intention was to outwit them or do harm to himself”. Several parents described how their children struggled with comorbid mental health disorders. Emily described her daughter’s diagnosis as “starting to look like alphabet soup” due to the high number of her daughter’s formal diagnosis. Her daughter required additional mental health support to contend with her diagnosis-related symptoms.

Some parents succeeded at finding supports to contend with their children’s risky behaviors and mental health disorders. Daphnie described having success with a residential program designed to address addiction, mental health issues, and self-harm behaviours stating that, “It’s the first time in 5 or 6 years that she’s stable.” Several parents reported that their children were attending or had been attending rehabilitation for alcohol abuse. The ability of the adult children to contend with the aforementioned addiction and mental health issues has implications for their futures. Risky behaviours including behaviours unrelated to mental health and addiction, not only resulted in jail time, but also made it difficult for adoptees to maintain employment.

“She seems to be able to find jobs. She has trouble holding on to them”: Difficulty maintaining employment. The majority of parents reported a pattern of sporadic child employment. The children often had multiple jobs in one year. Jocelyn discussed her daughter with FASD having had 18 jobs between the age of 18 and 24. Parents described how their children were always enthusiastic about a newly acquired work position, but soon discovered that they were ‘in over their heads’. Gabrielle describes the emergent work cycle, “They’re so

anxious to please and so anxious they have this new job, they're going to do so well. But with every passing day the expectations are more, and more, and then they realize they can't do it."

The children were then typically 'let go' from their respective jobs due to absences, miscommunications, a lack of focus, and/or a lack of skill. Parents reported that their children viewed their jobs as temporary but did not have the skills to do anything else. Lacking the appropriate skillset was very disheartening for the adoptees. Daphnie described her daughter's intense disappointment in her shortcomings at her job, and how she thinks "she can't do it 'cause she's too stupid."

Parents discussed how their children's primary disabilities, memory deficits in particular, were responsible for their children's mistakes on the job. According to the QRS-F, 76% of parents responded that their child 'can't pay attention for very long'. There were reports of adult children forgetting shifts due to their difficulty sustaining attention and difficulties with memory. Jocelyn explained, "there are other factors in FASD, behavioural factors, which render a lot of people affected unable to keep their work". To compensate for their children's deficits, parents often had to personally drive or ensure that their child got to work to ensure a greater likelihood of job success.

Although parents exerted considerable effort to ensure their children maintained their employment, they described a need for their children to have a job to do outside of the home to promote general self-esteem and to provide them with something to be proud of. Even small jobs for an hour or two were said to be helpful. Results from the QRS-F showed that 60% of parents thought that their adoptee 'has too much time on his/her hands'. A structured work position was requested by parents to occupy some of that time, and give them a purpose in life.

In summary, parents were experiencing three major areas that were acting as barriers to their children adapting to a normative adult life (e.g., independent, financially stable, etc.). Parents described a lack of housing for their children as adults, and discussed their children's resistance to the changes required to move into adulthood (e.g., moving or finding a job). Additionally, parents described few and overburdened available adult services, as well as their children's financial strain. Finally, parents reported their child's risky behaviour, which in part led to difficulties maintaining employment, causing further financial strain.

Discussion

This mixed methods study integrates interview and questionnaire evidence focusing on issues facing adoptive parents and their children's transition into adulthood. To the author's knowledge this is the first study regarding the experiences of parents concerning their grown adoptive children who have FASD. The demands on adoptive parents are extensive in the areas of adult living, financial management, and individual behaviour.

It appears that the adopted adult children with FASD were encountering the same types of demands found in the literature concerning the general adult FASD population (e.g., birth parents). For example, the majority of parents reported that their children were living within the family's home for at least one period of time during adulthood (i.e., dependent living). Their children's propensity to stay within the home is consistent with the statistics found in the aforementioned longitudinal studies stating that 69 to 80% of participants remained living within their parents' home (Clark et al., 2008; Streissguth & Kanter, 1997). The tendency for adult children to remain in the home is also consistent with the literature on emergent adulthood (Arnett, 2000).

Additionally parents reported a pattern of job instability in their children, which is also consistent with previous research pertaining to adults with FASD, who reported that 80% of participants had problems with employment (Streissguth & Kanter, 1997). The jobs were often lost due to poor choices (e.g., not attending work on time). Parents discussed how a lack of job stability acted as a barrier to their children's financial independence. Parents reported that job loss was often due to poor decision making. These issues are a trend of secondary disabilities found in individuals with FASD in general, and are not necessarily specific to individuals who have been adopted (Bertrand, 2009; Michaud & Temple, 2013). As adults, individuals with FASD are utilizing the same services as non-adoptees, and therefore were encountering the same types of issues.

It appears that children with FASD were struggling to move out of the emergent adulthood life stage into adulthood. The children were struggling with financial independence, as well as making independent and responsible decisions, all of which are part of adulthood (Arnett, 2000). Additionally, they were continuing their pattern of sporadically living within their parents' homes, or never leaving the home at all, well past the age of 25 (i.e. the end of emergent adulthood). Fifty percent of participants' children were over the age of 25, but they still exhibited behaviours consistent with emergent adulthood. Parents reported attempting to step in and assist their children with their transition into adulthood which was described as a source of perceived stress.

Parents described the transition into adulthood as a process of new, and sometimes overwhelming, demands. According to the FAAR model, the transition of the children into adulthood can be viewed as a period of crisis due to the change in each family member's roles, and the development of new capabilities to counter the growing demands (Patterson & Garwick,

1994a). To ensure bonadaptation, there are resources that need to be bolstered, such as semi-independent housing, and access to adult services like Ontario Works (Patterson, 1988).

The area of greatest concern for parents was the lack of resources pertaining to living arrangements. Research indicates that maintaining one place of residence for more than an average of 2.8 years can act as a protective factor against secondary disabilities such as incarceration (Streissguth & Kanter, 1997; Streissguth et al., 2004). Providing adult children with structured and stable living environments outside the home, where they can remain independent, would remove them from environments where they could be victimized or get in trouble with the law. Providing semi-independent housing would also relieve parents of the strain of worrying about the safety of their children, and the stressors related to their children constantly moving into and out of their home.

Another area of parental concern was qualification for services like the ODSP, which can be difficult for adults with FASD who do not have a formal diagnosis. Application can be more difficult with those who have an 'invisible' disability that does not have a physical identifier. Individuals who do not have any physical features associated with FAS appear 'normal', and those that do have the facial features often grow out of them (Streissguth, 1994). Individuals with FASD who do not exhibit facial features may therefore appear as if they are making bad decisions, rather than being affected by their disability, making it even more difficult to qualify for services (Chudley et al., 2005; Michaud & Temple, 2013). Other than formal services like ODSP, individuals with FASD rely on informal supports like their parents (Clark et al., 2008).

Due to the difficulties associated with qualifying for services, parents reported feeling stressed about their children's ability to manage their personal finances independently. They worried about their children's source of income, and what they would do with the money once

they had it. One method to improve their children's financial status is to streamline the application process and to create guidelines for qualifications specific to FASD. Creating an application process that is more easily navigated would help adult children gain access to financial funding, taking the burden off of parents. Parents reported that their children's disabilities are not viewed as 'severe enough' to warrant service access, regardless of their difficulties holding employment etc. One parent called for the education of service providers on the characteristics of adults with FASD to further avoid confusion about service qualification. Parents also discussed a need for someone to manage the money of those children who did qualify for services, in order to conserve the money they received.

Parents who reported a high need of both formal and informal supports have associated the lack of those supports with the lowering of relationship quality between themselves and their adopted child, resulting in a negative influence on the family as a whole (Reilly & Platz, 2003). Perceived levels of stress can be elevated when parents are faced with the challenges of obtaining necessary services, financial anxiety, and the uncertainty of the future (Bailey et al., 2005; Mellon, Wilgosh, McDonald, & Baine, 1993). When overwhelmed by the experience of too many demands, there may be an increase in strain on parents that could eventually lead to maladaptation (Glidden, Flaherty, & Mcglone, 2000).

A family's level of adaptation is on a spectrum from maladaptation to bonadaptation, and a family's level of adaptation changes over time (Patterson, 1988), therefore it is difficult to ascertain a conclusive level of family adaptation. The definition of adaptation, according to the FAAR model, is a balance of demands and capabilities. The use of interviews and questionnaires can help capture what families are experiencing when attempting to adapt to their child's transition into adulthood. According to the QRS-F, parents are experiencing moderate levels of

perceived stress, and that they are generally lacking in resources. The disequilibrium between parents' demands and resources suggest they are still adjusting to their children's transition into adulthood. Parents therefore require additional aid to bolster their capabilities to ameliorate the imbalance, thereby fostering greater adaptation.

Considerations and Future Directions

The use of mixed methods is a strength of this study. Mixed methods research ensures higher trustworthiness of the data than either the questionnaires or interviews would provide alone. Member checking was particularly helpful as participants were given the opportunity to respond to the findings, and inform the researchers of any missing information. The majority of participants responded and their feedback was positive, confirming the themes. Two participants emphasized a need for the inclusion of information such as a lack of jobs for adults with FASD. Those statements were then included in the analysis. Interrater reliability was also established through standardized interview training and discussion of themes with other researchers involved in the greater project. These methods strengthen the credibility of the themes.

Although the methods were rigorous, there were also several limitations to the study. First, there was the heavy reliance on support groups for participant recruitment. Individuals who do not make use of support group services may or may not be at different stages in the road to adaption. Support services were utilized as the gatekeepers to access parents because children move out of child services as they reach adulthood, making families of adult adoptees difficult to contact. An alternative method of accessing parents of children with FASD would have eliminated any biases.

The second limitation was the lack of information on the QRS-F for eight participants. All participants completed the questionnaires, but for eight of them there was at least one item

missing, rendering the researchers unable to calculate those participants' total scores. Although there were total scores for more than half of the participants, it may be that the missing participants would have yielded different results. Participants may have forgotten to answer, or they may have chosen not to answer the missing items. However, it was possible for researchers to examine the QRS-F by the individual item, as all participants completed the majority of the questions. Examining individual items on the QRS-F was useful as they pertained to, and supported, the interview themes. However, there were not always applicable items on the QRS-F for each subtheme. The QRS-F was primarily intended for use with parents of young children, and therefore omits adult related issues like a lack of appropriate housing.

The study also provides direction for future research. Further research examining the experiences of adult adoptees themselves would be beneficial in order to address what supports they feel they need to move into adulthood. The interviews in this study were conducted with parents, and they may be unaware of their children's activities outside of their home. Including both parents' and their children's viewpoints would also allow for further data triangulation, providing a more complete picture of the family's experience (Guest et al., 2012). The adult children could give a more subjective account of their struggle with personal issues like mental health, risky behaviours, and their difficulties with change.

Furthermore, future research should also be extended to birth families of children with FASD. In adulthood there are no adoption-specific resources, and therefore birth families are likely encountering similar needs as adoptive parents and their children. Birth families may differ from adoptive families in that birth parents may have FASD themselves, and therefore require even more supports than adoptive parents who do not have FASD (Denys, Rasmussen, & Henneveld, 2011). It is possible that birth parents who have FASD may themselves be struggling

to adapt to adulthood. In that case, both the birth parents and their adult children would be in need of adult services.

Conclusion

This study has shown that there are particular challenges for parents who wish to assist their children to adapt as they grow older, and move from emergent adulthood into full-fledged adulthood. Parents requested adequate and appropriate housing, in addition to work initiatives for adult children. Providing parents with those services will help balance the demands and capabilities related to their child's transition into adulthood, and facilitate the transition from adjustment to adaptation. Parents can act as protective factors for their children's secondary disabilities, and need the appropriate support to continue helping their adult children move forward from childhood to adulthood.

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Waving a Magic Wand: Supports for Families Raising Children with Autism and FASD in Ontario

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Abstract

The purpose of this paper to examine the experience of parents raising children with Fetal Alcohol Spectrum Disorder (FASD) and Autism Spectrum Disorder (ASD) during the middle childhood stage of their children's development. Furthermore, this research investigates parents' formal and informal support needs as they adapt to the demands of raising their children. Informed by the FAAR model, semi structured interviews, the Family Resource Scale, and the Family Crisis Oriented Personal Scales were completed by twenty-six parents of children with FASD and ASD. Using thematic analysis, four major themes were identified from the interviews including qualification for services and service availability, parent advocacy, and formal and informal supports. Each theme is discussed in detail. The questionnaires were analyzed using descriptive statistics, providing additional supporting evidence of the themes. The findings indicate that although there are services (e.g., respite care) available in Ontario, there are not enough services to satisfy parents' needs. Considerations and future directions for Autism and FASD related family research are discussed.

"Waving a magic wand": Supports for families raising children with Autism and FASD in Ontario

Research focusing on families of children with developmental disabilities is crucial for ascertaining what supports are most useful (e.g., support groups) for parents to adapt to demands on the family, as well as to help discern what the needs of those families are (Glidden, Kiphart, Willoughby, & Bush, 1993). Raising children with developmental disabilities can have a positive impact on the family and bring them great joy, as well as pose some unique disability related challenges (Grace, 1997). Some of the challenges families face and the supports they use to manage them are discussed below.

Supports for Families of Children with Developmental Disabilities

Family supports for families of children with developmental disabilities have been widely regarded as facilitative for family adaptation (e.g. McCubbin & Patterson, 1983; Perry, 2005; Wei et al., 2012). There are two general categories of supports: formal support and informal support. Formal support services can be defined as professional or paraprofessional services and/or interventions (e.g., counselling, respite care, parent support groups etc.; Ellis et al., 2002; Perry, 2005). Informal supports are defined as emotional backing or practical aid provided by family members and/or the larger community (Perry, 1989). Parents of children with developmental disabilities have reported that both formal and informal supports have been useful for managing their children's needs (White & Hastings, 2004).

Two supports directly requested by parents of children with developmental disabilities in North American literature are social support and respite care, and both are associated with decreased levels of perceived parental stress (Doig, McLennan, & Urichuk, 2009; Foti-Gervais, 2006; Hodgetts, Nicholas, & Zwaigenbaum, 2013; Macmullin, Tint, & Weiss, 2011; McGill,

Papachristoforou, & Cooper, 2006; Peer & Hillman, 2014; Strunk, 2010). Social support is one of the most commonly discussed supports in developmental disability literature, and evidence has shown that social support can have a positive impact on parents both psychologically and physically (Cantwell, Muldoon, & Gallagher, 2014; Wei et al., 2012; White & Hastings, 2004; Wodehouse & McGill, 2009). In addition to reducing stress-related physical symptoms, such as high blood pressure, the alleviation of stress connected to social support has improved parents' personal sense of general mental well-being (Cantwell et al., 2014; Glidden, Billings, & Jobe, 2006; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; White & Hastings, 2004; Wodehouse & McGill, 2009). Both formal and informal social resources have been associated with the aforementioned improvements (Ainbinder et al., 1998; Platz, 2004; Shu & Lung, 2005; Wei et al., 2012). Parents' high marriage quality and its associated positive social support have also been shown to increase parents' sense of wellbeing, and it is therefore important that parents take the time to maintain their relationships (Kersh et al., 2006).

When parents require personal time for themselves or each other, they can turn to respite care services for supervision of their child. Respite care is defined in Canada as time out for the caregiver, and is usually carried out through a worker coming into the home or having the child stay in a facility for 30 days or less (Dunbrack, 2003). Research evidence has indicated that respite care has a lasting positive effect on parents' psychological wellbeing, and respite care is sought out in particular by parents whose children exhibit typically aggressive behaviors (Hodgetts et al., 2013; Mullins, Aniol, Boyd, Page, & Chaney, 2002; Strunk, 2010). Although the need for respite care has been rated as high in Canada, parents have reported difficulty accessing formal services due to problems navigating confusing service systems and meeting

specific service requirements like acquiring a formal diagnosis for their child (Doig et al., 2009; Dunbrack, 2003; Watson, Hayes, Coons, & Radford-Paz, 2013; Watson, 2008).

Children with developmental disabilities frequently access formal services throughout their lifespan (Olson, Oti, Gelo, & Beck, 2009; Vogan et al., 2014). Individuals who have received early services and interventions have been found to have better long term outcomes than those who received them later in life (Bailey et al., 2005). Early intervention (i.e., formal supports) has been shown to be particularly important for Fetal Alcohol Spectrum Disorder (FASD) and Autism Spectrum Disorder (ASD) to promote better communication skills and prosocial behaviours (Bertrand, 2009).

Fetal Alcohol Spectrum Disorder and Autism Spectrum Disorder

FASD and ASD are neurodevelopmental disabilities, and individuals with those diagnoses typically require lifelong supports. FASD is an umbrella term that encompasses a continuum of symptoms that result from in utero alcohol exposure (Koren & Nulman, 2014; Rasmussen & Bisanz, 2009; Saddok & Saddok, 2007). FASD has a prevalence rate of approximately 9.1 per 1000 live births (Canada FASD Research Network, 2015; Health Canada, 2006). Children who fulfill all of the criteria fall on the severe end of the spectrum, and are referred to as having fetal alcohol syndrome (FAS). Individuals who do not fulfill the full criteria for FAS are defined as having partial fetal alcohol syndrome (pFAS), alcohol related birth defects (ARBD), or alcohol related neurodevelopmental disorder (ARND). The diagnostic process for FASD is continuously evolving, and usually requires a multidisciplinary team to make a formal medical diagnosis (Chudley et al., 2005; Chudley, Kilgour, Cranston, & Edwards, 2007). A diagnosis within the FASD spectrum is a medical diagnosis, and is not included in any version of the Diagnostic Statistical Manual (DSM; Chudley et al., 2005).

Unlike FASD, ASD is a clinical diagnosis and therefore is included in the DSM-IV-TR under the heading of Pervasive Developmental Disorders and in the current DSM-V as Autism Spectrum Disorder (American Psychiatric Association, 2000, 2013). ASD has a prevalence rate of 1 in 88 live births, and is currently characterized by four main criteria: persistent deficits in social communication, restricted and repetitive patterns of behaviour, behaviours must cause clinically significant impairment, and have an onset during the early developmental period (American Psychiatric Association, 2013). ASD occurs, like FASD, on a continuum and ranges from mild to severe.

The broad spectrum of behaviours exhibited by individuals who have ASD or FASD mean that they require a range of services that are tailored to each individual (Brown & Bednar, 2003; Chaplin, 2007; Watson, Hayes, et al., 2013). For example, individuals with severe ASD often manifest more maladaptive behaviours (e.g., aggression) than individuals with mild ASD, and therefore require different behavioural interventions than their mildly symptomatic counterparts (Matson, Wilkins, & Macken, 2008). Neurological disorders, like ASD and FASD, are also commonly comorbid with other disorders such as intellectual disabilities, which require their own respective supports and interventions (American Psychiatric Association, 2013). The unique needs of individuals with ASD and FASD can have a significant impact on the family (Hall & Graph, 2012; Olson et al., 2009).

Severe ASD and FASD related symptoms are considered contributing factors to some of the highest levels of perceived parental stress in the literature (Hayes & Watson, 2013; Watson, Coons, & Hayes, 2013; Watson, Hayes, et al., 2013). For example, high levels of perceived parental stress are thought to be related in part to the high frequency of maladaptive behaviours

associated with each disorder during childhood (Chudley et al., 2007; Hall & Graph, 2012; Shattuck et al., 2007; Streissguth et al., 2004). Individuals who have ASD or FASD often share similarities in communication and social deficits, which are also linked to higher levels of perceived stress in parents (Bishop, Gahagan, & Lord, 2007; Davis & Carter, 2008; Stevens, Nash, Koren, & Rovet, 2012). Additionally, children with these disorders are frequently highly dependent upon their parents throughout their lifetimes (Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008; Streissguth & Kanter, 1997; Vogan et al., 2014).

Parents contending with the aforementioned stressors like lifelong dependency, often require services (e.g., respite care) to assist them with those challenges. The accumulation of supports promotes a family's adaptation to their children's needs (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Macmullin et al., 2011; Nachshen & Minnes, 2005). A child's transition into middle childhood presents new stressors, such as a necessity for appropriate social skills in a structured school environment and the potential for bullying victimization, resulting in a need for formal skill building services (Neece & Baker, 2008; Rose, Simpson, & Moss, 2015). Family supports are an integral part of several adaptation models, which theorize that supports are conducive for optimal family adaptation (McCubbin & Patterson, 1983; Patterson, 1988; Perry, 2005).

The FAAR Model

One model including supports and their impact on the adaptation related capabilities of parents raising children with developmental disabilities is the Family Adjustment and Adaptation Response Model (FAAR; Patterson & Garwick, 1994, 1998; Patterson, 1988). Within the FAAR, the family endeavours to sustain good family functioning, or homeostasis, by utilizing their

capabilities including coping skills and resources. Capabilities can be associated with, and derived from, the individual, the family, and/or the community.

The FAAR Model is comprised of two phases that are separated by a crisis event (Patterson & Garwick, 1994a, 1998; Patterson, 1988). The first phase, called the adjustment phase, occurs when families use their existing capabilities to moderate any negative impacts from stressors or strains (Patterson, 1988). When the demands (i.e., stressors and strains) on a family overwhelm their capabilities, a crisis occurs, and families must make changes in their capabilities to compensate for the discrepancy. The adaptation phase occurs post crisis, when a family enhances and utilizes their range of capabilities in response to the demand-capability imbalance. For example, parents of school age children with maladaptive behaviours who struggle with getting their children ready for school can work with a behavioral therapist to design a morning routine to bolster their parenting skillset (Maul & Singer, 2009).

The FAAR model posits that families are continually in a state of flux between the adjustment and adaptation phases. Families encounter difficulty when they cannot adequately bolster their capabilities and are unable to adapt to a crisis, resulting in issues like perceived parental stress (Glidden et al., 2006). Families who experience difficulty improving their capabilities often turn to supports, both formal and informal, for additional aid with their coping skills and resources (Fontenot, 2007; Jones & Passey, 2004).

Research has shown that families of children with disabilities in the middle childhood cohort (ages 6-12) have had mixed levels of success with adapting to raising their children, resulting in different levels of perceived parental stress (Neece, Green, & Baker, 2012; Woodman, 2014). The varying adaptive outcomes shown in longitudinal studies appear to be due to differing individualized stressors such as disruptive child behaviours and a lack of resources in

early childhood (Azad, Blacher, & Marcoulides, 2013; Neece et al., 2012). Conversely, parental optimism has been highlighted as a protective factor for familial adaptation, and can be learned through formal support services (Ellingsen, Baker, Blacher, & Crnic, 2014). Stress related interventions have been recommended for families of children with disabilities, particularly for parents of children with externalizing behaviours (Azad et al., 2013; Neece et al., 2012).

Although FASD and ASD have some similarities with regards to behaviour (e.g., externalizing) and child life outcomes (i.e., possible lifelong dependency), research evidence indicates that there is a paucity of available supports specifically for individuals with FASD (Brown & Bednar, 2003; Watson, Hayes, et al., 2013). Ontario in particular has been lacking in FASD awareness and supports to the extent that the Provincial Government of Ontario has begun an initiative to create an FASD strategy for the provision of FASD-related services (Parliamentary Assistant Granville Andersib, 2015). Individuals with FASD in particular may be lacking available services, but parents of children with ASD and FASD have both reported similar stressors including the diagnostic process and challenging externalizing behaviours (Watson, Hayes, et al., 2013).

Previous research has shown some similarities between families of children with FASD and ASD with regards to the services they have used. For example, Ontarian parents of children with both types of disabilities discussed a need for the education of medical professionals and timely diagnosis for services (Watson, Hayes, et al., 2013). The present study will expand on these findings, with a focus on what supports parents require and what supports they actually use. To the author's knowledge, there are no other mixed methods studies regarding supports of families of school aged children with FASD and ASD in Ontario. Therefore, the purpose of this study is to identify the experiences of families raising children with FASD and ASD, and to

examine their formal and informal support needs as they adapt to the demands of raising their children in middle childhood. Resources like support services have been highlighted as important for parents' long term adaptation throughout middle childhood (Neece et al., 2012).

Methodology and Methods

Mixed Methods Research

A mixed methods research design was employed, which entailed the gathering and integration of both quantitative and qualitative data (Creswell, 2014; Teddlie & Tashakkori, 2009). The advantage of mixed methods, rather than employing a single method (i.e., qualitative or quantitative), is that using both methods allows for a greater degree of trustworthiness and facilitates a greater depth of topic examination (Creswell, 2014; Guest, MacQueen, & Namey, 2012; Teddlie & Tashakkori, 2009). The chosen mixed method analysis was called a convergent parallel design, where the questionnaire and interview data were analyzed individually and then compared and contrasted with each other (Creswell, 2014). The FASD and ASD groups were analyzed separately. The specific analyses performed are presented below.

Qualitative Interviews

Semi structured interviews were conducted with families of children with FASD and ASD. The interviews were administered following an inductive strategy called the basic interpretive approach, which endeavours to understand how individuals make meaning of a given situation (Merriam, 2002). Participants were asked 22 open ended questions, and prompts were used when necessary. The questions were informed by the FAAR (Patterson & Garwick, 1998). An example question is, "How do you manage all of your responsibilities?" Participants chose the time of the interview as well as the interview location at their convenience (e.g., coffee shops or family homes). Parents also chose to interview together or separately according to their

personal preferences. Parents were contacted via email when necessary for any follow up questions that arose during the analysis.

Qualitative Data Analysis

The interviews were analyzed using a six phase standardized model of Thematic Analysis, whereby researchers search for recurrent patterns of meaning across a data set (Braun & Clarke, 2006). A theoretical approach was used by which the FAAR model informed the interview questions and analysis (Braun & Clarke, 2006). All of the interviews were audio recorded and then transcribed verbatim. The transcriptions were reviewed several times to promote familiarity with the data. Notes were made during the reviewing process pertaining to possible codes and/or themes. The transcriptions were then reviewed again, and all relevant information was given a clearly defined code. The codes were then clustered into themes. One method used for defining themes is to search for the repetition of codes across the dataset (Braun & Clarke, 2006; Guest et al., 2012; Ryan & Bernard, 2003). Each theme showed evidence of internal homogeneity of the codes within each theme, and external heterogeneity of meaning from other themes (Patton, 1990). After the themes were clearly defined, they were labeled using quotations taken directly from the interviews, which augmented theme validity (Guest et al., 2012).

To improve the trustworthiness of a qualitative analysis, it is important to be as transparent about the analysis as possible (Guest et al., 2012). In addition to using direct quotes from the interviews, an audit trail and member checking were employed. The audit trail included descriptions of the process of developing the codes and themes, of the exclusionary theme criteria, and the chosen quotes for each them. Member checking was accomplished by emailing participants, providing them with a short theme report, and requesting their feedback.

Questionnaires

The Family Resource Scale (FRS) and the Family Crisis Oriented Personal Evaluation Scales (F-COPES) were completed by participants (Dunst & Leet, 1987; Dunst, Trivette, & Deal, 1988; McCubbin, Olson, & Larsen, 1981). Both measures were provided to participants either in person or were mailed via Canada Post. Further details on each scale are provided below.

The Family Resource Scale. The FRS measures the adequacy of resources and needs in households of families with young children (Dunst & Leet, 1987; Dunst et al., 1988). The questionnaire has been demonstrated to have good internal reliability with a coefficient alpha of 0.97, as well as sufficient test-retest reliability with a total scores stability coefficient of $r = 0.52$ (Dunst & Leet, 1987). Criterion validity for the FRS was also established (Dunst & Leet, 1987). The questionnaire contains 30 items assessing physical and human resources related to: food, shelter, financial resources, transportation, time, health care, etc. Answers are in a likert scale format, and parents must rate the adequacy of the resource. The answers include not at all adequate, seldom, adequate, sometimes adequate, usually adequate, almost always adequate, and does not apply. The response choices are associated with a number ranging from zero (not at all adequate) to five (almost always adequate). An example item is, "Money to buy necessities."

The Family Crisis Oriented Personal Evaluation Scales. The F-COPES was administered to identify problem solving and behavioural strategies used by families in difficult situations (McCubbin et al., 1981). The questionnaire demonstrated good internal consistency, with an overall Cronbach's alpha of .87 (McCubbin et al., 1981). The F-COPES contains 30 items assessing five areas of coping behavior related to: Acquiring Social Support, Reframing, Seeking Spiritual Support, Mobilizing Family to Acquire and Accept Help, and Passive

Appraisal. Higher scores indicate higher levels of coping and vice versa. The questions are provided in a likert scale format, ranging from strongly disagree to strongly agree. An example question is, "When we face problems or difficulties in our family, we respond by: Showing that we are strong."

Quantitative Analysis

The comparison of different sources of data for the purpose of providing additional supporting evidence is referred to as triangulation (Creswell, 2014). For example, a theme is presented with an applicable and corresponding questionnaire item from each questionnaire. Descriptive statistics are presented in an embedded format. The embedded format was selected because the emphasis of the paper is placed on the qualitative interviews, and the function of the quantitative data is to provide further theme support (Creswell, 2014). The small sample size, the ordinal and categorical format of the questionnaire data, and the exploratory nature of the study prevents the majority of statistical analyses, with the exception of descriptive statistics (e.g., percentages and averages).

Participants

A total of 26 participants were recruited through FASD and ASD support organizations located across Ontario. Emails were sent to the agencies, who directed participants to contact the lead researcher should they wish to participate. The research team also used a respondent sampling recruiting method, where they contacted known individuals for recruitment assistance (Salganik & Heckathorn, 2004). The data was gathered as part of the larger family project, however only the information for parents of school age children was examined for the purpose of this study. Parents included adoptive parents, step parents, and birth parents (all referred to as parents). The selection of parents from the larger project's dataset was conducted by age

matching between children with FASD and ASD, ensuring they had similar child age groups. The same number of families were chosen at random from within each age category (e.g., 6-8). The children ranged in age from 3 to 12, with a mean age of 8. Parents range in age from 28 to 71, with a mean age of 40. All parents had at least one school aged child with FASD or ASD. For additional demographic information please refer to Table 1.

Table 1

Participant Demographics

	FASD		ASD	
Parent Characteristic	n	%	n	%
Gender				
Male	5	61.5	6	46.2
Female	8	38.5	7	53.8
Marital Status				
Married	11	84.6	13	100.0
Common Law	2	15.4	-	-
Number of Children with DD per Family				
One	13	100.0	13	100.0
Two	4	30.8	3	23.1
Three	-	-	2	15.4
Four	-	-	1	7.7

Note: DD = Developmental Disability

Results

All parents identified significant family assets, including personal resources and supports external to the family. Pseudonyms were used to protect the identity of participants. Through the use of Thematic Analysis, four major themes emerged from the resource related issues raised by parents during the interviews (Braun & Clarke, 2006). These themes included difficulty with the qualification for services and service availability, the necessity for parent advocacy, and identified areas of improvement of both informal and formal supports. The questionnaire data supported and provided further evidence for the themes.

Qualification for Services and Service Availability

Parents reported difficulty with having their children qualify for services, and with actually obtaining those services once their children were deemed qualified (e.g., respite care). All parents spoke about the necessity of a formal diagnosis for a greater ease of service access. Parents of children with ASD highlighted the importance of specific and adequately written psychological reports, and their impact on school service acquisition. Parents of children with FASD discussed the need for FASD recognition in all Ontarian schools. The children with FASD and ASD who did manage to qualify for their desired service were commonly placed on extensive waiting lists.

"In order to get proper services, they needed a firm diagnosis": The necessity of a diagnosis for service access. Parents discussed how services such as respite care services, school-related services, and therapeutic services required a disability diagnosis for child admittance. According to the F-COPES, 88% of parents reported seeking assistance from community agencies and programs designed to help families in their situation; however, not all children qualified for those services. Melanie, a mother of four boys with ASD described the difficulty, "If you're just dealing with behaviours, you get no services. If you have a piece of paper that says that your child is autistic, you can access respite, you can access special services". Karen, a mother of two sons with FASD said, "We can't get them extra help unless they have a [formal FAS] diagnosis".

In addition to the need for a formal diagnosis, parents of children with ASD discussed a need for professional ASD diagnostic precision when attempting to access school system services. Psychological reports were described as crucial to the education system's service decision making process. Mark recounted the impact of subtle differences in how children's

psychological assessments are written, “If you’re looking into school services, if they write a certain phrase, they won’t give you the right services.” Parents noted that including the language of a moderate or mild diagnosis in reports created a barrier to accessing needed services. Carla, mother of a child with mild ASD spoke of her experiences, “What are they gonna offer and does he even qualify? Because he’s mild and, oh well, we deal with the more severe cases first. Fair enough, but in the meantime, I’m still having to deal with this.” Anna, mother to two sons with ASD, spoke about her experiences specifically accessing Intensive Behavioral Intervention (IBI),

> It’s very specific criteria to see if you can get in it, so they decide who’s a candidate and who isn’t, so they’ll say oh well, you know, he’s not severe, not diagnosed as moderate or severe so he doesn’t qualify, yet he can’t function in a regular classroom.

In contrast to parents of children with ASD who have established supports like IBI both in the community and the school systems, several parents of children with FASD discussed difficulty with school boards acknowledging their children’s FASD as a disability at all. Veronica discussed the need for, “Getting the school to recognize it because our school board doesn’t recognize FAS.” Leslie also described how “FAS is still not really recognized as a disability in Ontario.” A lack of a label also makes it difficult for teachers to form a plan of action. Nina, a school teacher and mother of a girl with FASD, described the need for an FASD label in the school systems, “it’s really crucial I think for the teachers too. To have something that they can hang their hat on and say this is the child’s problem, and so then you can get all the help that you can.” Other children’s schools did acknowledge FASD, resulting in successful access to services. Jodi described her experience, “It was a big deal telling the school and they kind of just took it and ran with it on their own.” Patricia was thrilled when her doctor wrote a report specifically for her daughter’s school, “he put down in her report, this child needs x, y,

and z. She's gonna need it consistently at school. She will need more supervision than the average child. She will need an EA [educational assistant]." Because of the formal FASD diagnosis, she received the services she requested.

There were also accounts of professionals simply denying FASD as a diagnosis. Patricia described a doctor who said, "Well in Italy, they drink all the time and you don't see anybody with FASD over there" and that after seeing four doctors, "he was the closest to understanding FASD." Leslie had a similar encounter where the principal at her school denied FAS as a disability and he, "felt that by modifying their behaviour he could get them out of whatever they were in." Encountering professionals who do not treat FASD as a disability prevents children from receiving a diagnosis, which then prevents parents and the child with FASD from receiving the services they require. However, many of the children who did manage to qualify for access to services were placed on waiting lists, and waited extended periods of time to receive them.

"The waiting lists on the different types of services are crazy": Extensive waiting lists. Parents reported that the waiting lists for services both for children with FASD and ASD were considered to be extremely lengthy. Services like diagnostic assessments, respite care, and therapy can take years for parents to gain entry. Katrina, mother to a son with ASD, described her experience when seeking out financial assistance for services, "I was told there was a waiting list and I said, as in years or months? She's all-I wouldn't count on months." Several parents turned to private services and paid for them out of their own pocket in order to gain access to some help more promptly.

Seventy-three percent of parents with ASD described being placed on an unreasonably long waiting list at least one point in time during their interview. Roger, father of a son with ASD, recounted being told about two year waiting lists. Jackie, mother to four children with

ASD, described her experience with waiting lists, “well it wasn’t hard to access them [services], it was just hard to get the services and get off the wait list.” The wait list was a concern for parents who know that early intervention for ASD is important. Anna reported feelings of frustration towards the overburdened system, “I’m supposed to wait and do nothing, like a lot of parents do nothing. I can’t do nothing.” Some parents were particularly concerned about long waiting lists for IBI, which is an intensive application of Applied Behaviour Analysis (ABA), and is currently the gold standard for ASD behaviour management (Kopellman, Lindgren, & Wacker, 2015). For example, Melanie reported, “And I don’t know how long that list is, you know? They’re cutting back with IBI and stuff like that.” She went on to say that if she could wave a magic wand, she would put her child “in IBI tomorrow.” Ethan and Carla waited for IBI for a year before they found out their child was not qualified for IBI, and so they turned to paying for private services, like speech therapy, for their five-year-old son. Ethan explained, “I can’t wait anymore. He needs it now.”

Several parents of children with FASD expressed the same dissatisfaction with the long wait lists as did the parents of children with ASD. Leslie described her process of procuring services for her children post diagnosis, “Everything was fairly slow moving. You know, eight to ten months to a year.” Nonetheless, once parents received the services, they were not always adequate. Jodi reported spending the same amount of time waiting on counselling sessions, which turned out to be frustratingly insufficient, “he was on the wait list for about a year and then they get 10 sessions and that’s it.” When asked what services Patricia would desire if she had a magic wand she responded, “I would banish the waiting lists and things like that. We’ve been on a wait list for almost four years for the one particular special service at home.” The wait

lists motivated, in part, both groups of parents to take on the role of parent advocate, and to push for the services their children require.

Parent Advocacy

All parents spoke about taking on the role of parent advocate on behalf of their children. Katrina summed up her experience as a parent advocate, "You have to speak up, because if you don't speak up, you're not going to get what you need." Parents discussed the necessity to be outspoken, and to push for the services that their children required. They recounted researching and networking to educate themselves regarding their children's diagnosis, and the available services.

Tracey, mother of a daughter with FASD described her role as a parental advocate, "You have to fight for everything for those children. And you have to be on top of everything for them." Parents talked about the relentless drive required to access services. The terms "push, push push," and "bug, bug, bug" were used to describe parents' method of frequently approaching service organizations for admittance. In order to approach services more effectively, parents engaged in a lot of self-education regarding what services were available and how they work. Carol described how it was left to her alone to learn about and attend to her child's disability related needs:

> Don't take no for an answer. Follow your gut and do as much research as you can, because you have to learn. You cannot expect, ever expect, someone at the school to take care of him, the doctor, or anybody- it's up to you.

Karen also felt strongly that parents need to problem solve and get educated about their child's disability stating that, "absolutely you need education on FAS issues and support." In an effort to self-educate, Tamara described how, "we looked online, we read some things." Parents also gave

suggestions for sources of information that other parents of children with FASD and ASD could use for self- education. Mark suggested, "talking to other parents" for advice. Anna suggested, "If you've got the money, hire a lawyer to come with you," because of lawyers' knowledge surrounding children's service entitlements. Jodi recommended asking anyone and everyone for help/advice, "it depends on who you talk to at each place, what you can get and where else they direct you."

Parents' strong sense of advocacy was reflected in scores on the F-COPES. Parents completed the 'Mobilizing Family to Acquire and Accept Help' subscale, which measures, "the family's ability to seek out community resources and accept help from others" (McCubbin et al., 1981, p.479). Mothers scored on average in the 71st percentile (M = 14.87, SD = 3.48), which falls within the average range within this domain (i.e., the 15th to the 85th percentile). In contrast, fathers scored on average in the 99th percentile (M = 14.30, SD = 1.49). Unfortunately, statistical testing to look for a significant difference between those scores could not be accomplished due to the low sample size. However, it does appear that parents generally possess the skill set they require to seek out formal services in times of need.

Formal Support

Despite parents' skills at advocating on behalf of their children, parents of children with ASD and FASD asserted that there are some formal supports still lacking in Ontario. Parents were dissatisfied with some of the professionals they had encountered, and discussed a need for better professional education. Additionally, parents reported a need for more child supervision outside of school hours and during school holidays.

"They need supports after school, clubs, places to go": More child supervision services. Although parents were receiving some respite care, they discussed a general need for additional respite care services. Specifically, some parents reported difficulties finding supervision for their children between the end of their child's school day and the end of their work day. Parents also reported struggling to find activities for their children during school holidays. Nina described her children's extended school vacations for which she is forced to find extra supervision for them, "Summertime, Christmas holidays, maybe she could have one day off or something, but a whole week of days off that are just totally empty are the biggest challenge I see right now."

Parents did report receiving some respite care services to help with those unsupervised time periods, but that the amount of hours received were deemed inadequate. Melanie described her "luck" receiving 3 nights of respite care for her 3 children, "That's a lot compared to a lot of people when you have just one child that has Autism or any kind of problem. I think you get, what, a half hour a week?" Shane, father of a daughter with FASD highlighted respite care and the importance of adequate services, "to give the family a break because I think everybody needs a break from the intensity of -just to have a meal, be able to have a normal meal would be really nice."

Some parents reported settling for supervision sources outside of formal respite care because of the lack of alternatives. For example, Rebekah discussed a mediocre student run after school program saying that, "I guess they [students] are cheap enough that they can have more." Leslie described turning to her parents for supervision, "I would love a babysitter who dealt with kids with special needs. So that I had somebody that I trusted, from our parents." In addition to

more knowledgeable workers for supervision, parents also discussed the need for more educated professionals.

"It's inconsistent throughout every school, it's not the same, it's you know, great at some, really awful at others": The need to educate professionals. Parents provided a mixed review of professionals including educators, medical professionals, and psychologists. Parents described positive encounters with professionals who were knowledgeable about FASD and ASD. Conversely, parents described frustrating interactions with professionals who 'just didn't get it'. The education system was highlighted as being particularly inconsistent in the provision and quality of special education services.

Parents of children with ASD described successful experiences dealing with professionals who were well trained in ASD and its associated therapies like Applied Behavioural Analysis (ABA). Carl described his child's current teacher as, "very open, very willing to look at different alternatives and different things." Katrina discussed her satisfactory dealings with a social worker, "she would come and would offer actually some good suggestions." However, most parents of children with ASD felt that formal services in Ontario were adequate.

According to parents of children with ASD, doctors, social workers, and educators still require better or more training pertaining to both ASD diagnosis and management. Matt recalled working with a particular social worker who was working beyond her area of expertise, "We were getting bizarre advice from this woman, like have your kid put in an MRI and it's like, but why?" Jackie described the lack of training for educators in ABA, even though ABA training is mandated by the government, "you say to the teacher at the IEP what are your credentials in ABA? And they go what's ABA?" Several parents commented that new staff are struggling without sufficient training. Melanie described a teacher she was dealing with, "The teacher was

very, very new and didn't really understand Autism and just didn't, the communication just wasn't there." Katrina discussed having witnessed individuals who administered IBI programs who, "have teacher's aid papers and that's it." Parents of children with FASD also called for the education of professionals.

Parents of children with FASD discussed how professionals who *did* know about FASD, often were not knowledgeable enough to offer practical help. Practitioners in various fields often referred parents to other professionals for help. Kevin reported his experiences with his child's doctor, "Any time we asked him a question, he always knew the person or knew of a person" to refer him to. Karen described the experience of teachers she has encountered during her work with a school board, "a whole lot of them know a little bit about it but not really what it's like, how to deal with it, how to support these children." Leslie described her experience with professionals in general, "Most people will research things for us or look things up for us. But we haven't really come across anybody who's actually knowledgeable about it." The lack of professional knowledge regarding FASD is problematic considering the importance of early diagnosis and intervention for better life outcomes like success at school (Centers for Disease Control and Prevention, 2015; Streissguth, Barr, Kogan, & Bookstein, 1997). Parents also required support beyond the scope of what professionals could provide, including close relationships, and consequently turned to each other and family members for social support.

Informal Support

All parents discussed a need for social support, both internal and external to the family. Parents turned to friends and extended family with mixed results. The majority of parents discussed the importance of relationships with individuals in similar circumstances for advice

and social support. Additionally, parents described their reliance on each other as a couple for both practical and emotional support.

"We support each other a ton, you know, we do. We really have to team up": The tag team approach. Parents reported supporting each other emotionally and splitting up daily tasks. For example, parents described delegating before school activities to one parent and after school activities to another. Sharing tasks allowed parents to work, spend time with their other children, and take the time to recharge.

Both parents of children with ASD and FASD discussed sharing daily tasks to ease the demand on each other. Rebekkah reported reaching out to her husband when she was feeling overwhelmed, "If I am with the kids and I'm not coping, I don't feel bad to wake Roger up and say it's eight in the morning and they've been up since six. I need help". Melanie described her and her husband's routine, "He'll do the morning routine, get them off to school, and then at night I do the stuff." Sharing daily tasks also enabled parents to take some personal time. Patricia and her husband used the time away from the kids to take care of their health, "Like we both do a lot of fitness and working out and we spell each other off that way."

Couples often turned to each other for support or advice. At the time the study was conducted all parents were either married or in a common law relationship. Shane described how he and his wife supported each other emotionally and practically, "I'm the support worker in the team, you know? We're together and I support her but she leads, corrects me, helps us." Carol discussed the importance of having a partner for emotional support, "I'd say you know what- it's just getting to me, and then he would be my rock, and then he would do it for me, and I would be his rock." Jackie also described her husband as her "rock" and how, "It is stressful, but I'm lucky

I have a good partner, my husband." Although parents' supportive contributions were highly valued, parents also turned to friends and the larger community.

"You've always got to have support. There's no way, like I said before, there's no way that you can do it on your own": A social network is a necessity. All parents described the need to turn to other individuals for support including, friends, family and support groups. Parents reported that relationships with individuals who have gone through similar circumstances to be of particular importance, due to their empathy and practical advice. Parents also described negative experiences with friends and family who did not understand the children's diagnosis or related behaviours.

Parents found support groups to be useful as a place to discuss their feelings, and seek out advice. Parents described the value of having an outlet in which to vent. Anna described her online ASD support group, "We're all on Facebook so we can bitch back and forth to each other and stuff." Veronica also found her FASD online support group emotionally helpful, "It's a website with all, you know, parents who have adopted FAS children. If you're having a crappy day basically, you can just type, post, and yeah there's support." Nina attended a FASD support group in person with parents who shared similar life circumstances and described her general experience,

> I've gotten to know them a little bit more as friends now, and it's a very safe place to go and to talk about what's going on in our family. You realize- and that's where I learned a lot too, like hey what's going on in our family that goes on in other families as well, and we're not just so crazy and you learn strategies to help.

In addition to support groups, parents turned to their family members for support. Rebekkah described relying on her father for child supervision, "So when he's here it really

gives me and Roger an opportunity at night when the kids are sleeping, we could go for a walk, he's here in the house. We know that if the kids wake up everything's OK." Tracy shared a similar experience with her extended family who stepped in to offer her some respite, "They help, you know. My sister in law- Friday, tomorrow evening, she'll take her and have her until Sunday." Ethan described his son's love for his grandmother and aunt, "We lean on them most because they understand him, have patience with him, and he loves them to death."

Conversely, four parents of children with FASD described family members who did not understand FASD. Jodi reported her experience with her extended family, "It's awkward because they know that he has FASD but I don't know if all of them really know what that means and so they don't treat him accordingly." The FASD diagnosis changed Patricia's interactions with part of her family, "It changes, I mean extended family dynamics. Some family members don't understand the diagnosis. Some people were super willing to read anything I gave them." Tamara's parents were receptive, but still didn't quite understand what she was going through, "You can talk to them about it but they don't really understand the situation."

Parents of children with ASD also encountered misunderstandings about their child's disability. Katrina recounted the experience of telling her family that her child had ASD, "The initial response from everybody is -no- there's nothing wrong with him because they all think, well you know, handicapped kid and he doesn't look like it." Melanie described her experiences with her brother, "who really doesn't care to know anything about Autism and they assume your children are rude." Carol's family were similarly unsupportive, "I didn't talk to my family at all. I still don't talk to my family about it, because they don't, I don't know that they really truly believe that it's a true diagnosis." The lack of consistent support from family and friends was also reflected in the questionnaire data.

On the FRS, participants were asked to rate the extent to which they had someone to talk to (FRS). Forty-six percent of parents of children with ASD chose almost always adequate, indicating that the majority of parents do not always have someone to talk to. Parents of children with FASD indicated they required even more additional social support than parents of children with ASD. The majority (42%) of parents of children with FASD chose usually adequate and the rest scored below that category. Additionally participants completed the F-COPES subscale called Acquiring Social Support, which measures "a family's ability to engage in acquiring support from relatives, friends, neighbours, and extended family" (McCubbin et al., 1981, p.479). All parents scored within the average percentile range on the Acquiring Social Support subscale (M = 23.88, SD = 7.52). It appears that mothers in particular do not believe that they are adequately socially supported in comparison to their partners, with the majority ranking in the low average range. Results indicate that parents are generally able to access social support within their families and the greater community; however, according to the FRS, parents still feel as if they require someone to talk to.

In summary, parents discussed four major areas pertaining to the attainment and use of formal and informal services. Parents described how a formal diagnosis is necessary to qualify for service access, particularly in the school system (e.g. Educational Assistant), and how they were often placed on overly long waiting lists to utilize the services. Additionally, parents highlighted their responsibility to act as advocates on behalf of their children to acquire the necessary services. Parents also described important formal and informal services. Formal services like child supervision were reported to be highly valued, and parents reported a need for the education of professionals. Finally, parents reported the necessity of informal supports,

including the need to team up as a couple and to maintain a social network for practical, emotional, and informative purposes.

Discussion

The present mixed methods study incorporated interview and questionnaire evidence concentrating on the support related needs of parents raising school age children with FASD and ASD in Ontario. Parents discussed what worked for them and what services required improvement. Parents described the impact of a diagnosis, for better or for worse, on the qualification of services. They also described the necessity of advocacy on behalf of their children, and the usefulness of social support.

All parents endorsed social support as essential for facilitating adaption in relation to raising their children with developmental disabilities. Parents reported turning to each other as a primary social resource. The need for social support is consistent with a large body of related literature (Glidden et al., 2006; Kersh et al., 2006; White & Hastings, 2004). Parents discussed family members' usefulness for emotional and practical support, and how that resource was associated with a decrease in perceived stress. The opposite was true of parents who encountered family members who were unsupportive. Parents described frustration with friends and family who did not understand their children's diagnosis. The stress associated with a lack of social support was also consistent with other developmental disability literature (Boyd, 2002; Foti-Gervais, 2006).

Despite parents' endorsements of social resources, it appears that parents were not able to adequately access them. Questionnaire data (FRS and F-COPES), indicated that parents of children with FASD had access to someone to talk to less often than parents with children who have ASD. Parents of children with FASD may be experiencing a lack of social support because

FASD is often an invisible disability with minimal facial features, and there is a lack of general public knowledge surrounding that disability (Chudley, 2008; Fetal Alcohol Spectrum Disorder Ontario Network of Expertise, 2010). A couple of parents even founded their own support groups to compensate for the lack of social support.

All parents also recounted actively searching for services for their children. Many parents labelled themselves as advocates for their children. There are numerous accounts of parents advocating for their children's services in the literature (Foti-Gervais, 2006; Jones & Passey, 2004; Watson, Hayes, et al., 2013). Early intervention for parents of children with developmental disabilities can teach them the skillset they need to advocate with professionals, which promotes a sense of empowerment (Bailey et al., 2005).

In addition to the discussion surrounding supports for parents of children with FASD and ASD, there were also barriers to adaptation regarding service qualification and availability. Parents described the need for a diagnosis, and how difficult it can be for individuals with mild or moderate symptoms to obtain services. The difficulties surrounding diagnosis are consistent with previous research by Watson et al. (2013). Parents of FASD in particular found that services, including the education system, sometimes did not fully acknowledge FASD, or did not know how to support individuals with FASD effectively. The acknowledgement of FASD as a disability in Ontario has been improving as the government has been working on the aforementioned province wide strategy to address FASD and its associated services (Parliamentary Assistant Granville Andersib, 2015). As a consequence of the roundtable report, an education update was put forward asking schools to submit applications for additional services related to FASD and other developmental disabilities (Ministry of Education, 2015).

However, the FASD initiative is in its infancy, and whether or not those services will be delivered remains to be seen.

A second barrier to adaptation was the lack of child supervision services including respite and afterschool programs. The Ontario education system institutes week long holidays (i.e., Christmas and March break) in addition to summer holidays, during which time parents require supervision for their children. For example, parents suggested adding more flexible summer camp programs with adequately trained staff. Families of children with ASD and FASD face additional challenges when seeking supervision because disability related externalizing behaviours often require formal respite care rather than an informal local babysitter. Parents of children with problematic behaviours can also experience difficulty with their child's expulsion from respite care programs, further placing them at difficulty for finding adequate supervision services (McGill et al., 2006).

Although previous literature was unclear on the abilities of families to adapt to raising their middle school aged children with developmental disabilities, this study suggests that there is still room for improvement (Neece et al., 2012; Woodman, 2014). According to the FAAR model, adaptation is achieved when there is a balance of demands and capabilities (Patterson, 1988). All parents reported advocating for their child and, according to the F-COPES 88% of parents were seeking assistance from community programs. Parents also appear to be accessing low average levels of social support, as determined by F-COPES percentiles. There do appear to be services available, like respite care, but there is not an adequate amount of services and year long waiting lists are common.

Addressing the aforementioned issues can help parents balance their demands with even stronger capabilities, further improving adaptation. Although most FASD interventions currently

lack enough empirical evidence to support empirical validation, there is research to suggest that early diagnosis before the age of six and early service involvement can reduce the likelihood or impact of secondary disabilities (Bertrand, 2009; Centers for Disease Control and Prevention, 2015; Streissguth et al., 1997). Additionally it has been established in ASD literature that prompt diagnosis and subsequent early interventions, like IBI, predict the most successful treatment outcomes (Perry et al., 2008; Plauche Johnson & Myers, 2007). Adaptation in middle childhood is important because adaptive success through early intervention at this time can have long lasting positive impacts on families (Bailey et al., 2005).

Considerations and Future Directions

The greatest strength of the study is the use of mixed methods research. The integration of the questionnaires and interviews lends the themes additional credibility than either body of data could provide alone. Steps were taken to maximize trustworthiness of the data including member checking, standardized interview training, and the discussion of themes with other project researchers. Additionally, member checking was used whereby participants were offered the opportunity to provide feedback on the themes. Participant feedback was positive and confirmatory of the themes.

A second strength of the study is the method of age matching used for participant selection from the larger project's database. Every family had at least one child with FASD or ASD whose age fell in the middle childhood range, ensuring that parents would have been more likely to have encountered similar age related milestones (e.g., their children attend school). Due to the similarity in their children's ages, parents were also exposed to similar stressors, such as requiring more child supervision during school vacations.

Despite the rigour of the methods used, there were several limitations. The first limitation concerns the recruitment source, which consisted primarily of support groups. Individuals who attend support groups may exhibit different personal characteristics than those who do not. For example, research has shown that individuals who attend support groups have experienced an increase in subjective well-being, mental health, and social support (Boyd, 2002; Shu & Lung, 2005; Wei et al., 2012). It is therefore possible that parents who have regularly attended support groups may be at a later stage of adaptation than those who have not attended a support group. Support groups were chosen as the point of access to parents due to a lack of alternatives. To eliminate any biases, it would be beneficial to conduct a study including participants who did not participate in support groups.

The second limitation is that parents' socioeconomic status (SES) and level of education were not accounted for. Many parents either forgot, or declined, to respond to the items associated with SES and education level on the demographic questionnaire. Socioeconomic status and parents' level of education should be considered in future studies because higher levels of both factors can positively impact children's level of functioning and life outcomes (Fountain, Winter, & Bearman, 2012; Paley, O'Connor, Frankel, & Marquardt, 2006). Parents with a higher socioeconomic status are more likely to have access to privatized services such as tutors or therapy because they can afford those services.

A third caveat to the study is that the diagnostic criteria of ASD and FASD are constantly evolving (American Psychiatric Association, 2000, 2013; Chudley et al., 2005). For example, in the current diagnostic manual ASD is considered to be a spectrum, whereas there are separate diagnostic categories in the DSM-IV-TR (e.g., Asperger's). Qualification for services may have changed in accordance with the disability criteria modifications, which may or may not have

impacted parents' service experiences. Future research regarding the impact of diagnostic change on service access would be beneficial as professionals shift to using the new criteria.

Conclusion

This study has shown that supports need to be tailored to each child's individual needs. ASD and FASD both occur on a spectrum, and available resources should reflect that diversity. Parents of children with both disabilities acted as expert advocates of their children's needs, felt that formal services regarding child supervision were lacking, and that professionals require additional training regarding developmental disabilities. Parents also highlighted the necessity of obtaining social support whether it be through friends, family, or support groups. Providing school age children who have ASD or FASD with the appropriate services will lead to more positive life outcomes, and facilitate family adaptation as they progress through their developmental stages.

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Chapter 4: Conclusion

The purpose of this manuscript-based thesis was to contribute to the existing literature addressing the experiences of families adapting to raising children with Autism Spectrum Disorder (ASD) and Fetal Alcohol Spectrum Disorder (FASD), with a specific focus on the supports they require. In this chapter the results from the two studies are summarized, and the answers to the research questions posed in chapter one are presented. Subsequently, the applicability of the Family Adjustment and Adaptation Response Model (FAAR) to the present research is discussed (Patterson & Garwick, 1994a, 1994b; Patterson, 1988). Finally, the chapter concludes with a discussion of considerations and suggestions for future research.

4.1 Summary of Findings

The first article titled "Well where's he supposed to live?": Experiences of Adoptive Parents of adult children with FASD in Ontario" was an exploratory study examining parents' experiences raising adult children with FASD using a convergent parallel mixed methods design. The needs of adoptive parents, and parents in general, are important as they can act as protective factors for their children's life outcomes (Streissguth et al., 2004). Parents who believe they lack required adult supports report experiencing increased stress due to their fear of negative future outcomes, yet little is known about adoptive parents at this stage of their children's lives (James Williams et al., 2011; Michaud & Temple, 2013; Watson, Coons, et al., 2013; Watson, Hayes, et al., 2013). The QRS-F (Friedrich et al., 1983) and semi structured interview questions were completed by 20 parents, and were chosen in accordance with the FAAR model (Patterson & Garwick, 1994a; Patterson, 1988) and a basic interpretive approach (Merriam, 2002). The interviews were analyzed using Interpretative Phenomenological Analysis (Smith et al., 2009), and the QRS-F was analyzed using descriptive statistics, such as means and percentages. Three

major themes were identified from the analysis, including housing and transition into adult housing, managing money/finances, and individual characteristics. Parents indicated they were moderately stressed on the QRS-F. The results of this study indicate that parents of adult children with FASD are significantly lacking adult resources for their children, which creates a substantial barrier for adaptation.

Additionally, there is a lack of consensus in research regarding the adaptation of parents to raising children with disabilities in the middle childhood age cohort (Neece et al., 2012; Woodman, 2014). Previous research has found that two factors have been implicated in the varying levels of adaptation of parents raising children in middle childhood, including maladaptive child behaviours and a lack of resources (Azad et al., 2013; Neece et al., 2012). The necessity of appropriate resources inspired the second article titled "Waving a magic wand: Supports for families raising children with ASD and FASD in Ontario," which was a parallel mixed methods design examining the resources parents used when raising school aged children with ASD or FASD. Twenty six parents completed the Family Resource Scale (Dunst & Leet, 1987; Dunst, Trivette, & Deal, 1988) and the Family Crisis Oriented Personal Scale (McCubbin et al., 1981), which were then analyzed using descriptive statistics. The same semi structured interview as the previous study was administered, but analysis was conducted using Thematic Analysis instead of IPA. Thematic Analysis was chosen due to the narrower topic of family supports, rather than looking at parents' general experiences (Braun & Clarke, 2006). Although all interview questions were analyzed, answers specifically including supports and their impact on parents were the focus of analysis, as opposed to answers concerning other issues such as family dynamics or the meanings caregivers ascribed to being a parent. For example, one area of analytic interest was the supports that parents already used and what services they desired. Four

major themes were identified through the analysis, including qualification for services and service availability, parent advocacy, and formal and informal supports. The results of this study indicate that although there are resources available to Ontarian parents (e.g., respite care), there are not enough services to satisfy family needs. Parents also demonstrated positive adaptive strategies. For example, all parents reported acting as advocates on behalf of their children.

4.2 Parents' Adaptation to Raising their Children with FASD and ASD

According to the FAAR model, adaptation is on a spectrum ranging from maladaptation to bonadaptation, and a family's level of adaptation changes over time (Patterson, 1988). Adaptation occurs when a family is able to achieve a balance between their demands and capabilities (Patterson, 1988). The aforementioned studies answered the following adaptation related questions: 1) Are parents adapting to raising their children as their children transition into a new developmental stage (i.e., middle childhood and adulthood)? 2) What supports do parents require to facilitate bonadaptation? There are services available in Ontario for both children and adults with ASD and FASD. However, parents of adult children with FASD appear to remain in the adjustment stage, due to a lack of adult resources and, as a result, experienced increased perceived stress levels.

According to the FAAR model, parents raising school age children with ASD and FASD appeared to be successfully adapting to raising their children, due to a variety of their capabilities. For example, parents reported mobilizing available resources, acting as advocates on their children's behalf, and searching for more and/or better services, which is consistent with previous research (Bayat, 2007; Olson et al., 2009; Watson, Hayes, et al., 2013).

Even though parents demonstrated great resourcefulness though service acquirement, they required more (e.g., additional hours) of those services to contend with stressors such as a need for child supervision during school vacations. Participants also reported extensive waiting lists for existing services, and several parents resorted to paying for private services for quicker access to resources.

In contrast to parents of school age children, parents of adult children with FASD appeared to be experiencing maladaptation, or to be remaining in the adjustment phase of the FAAR model, as they attempted to adapt to their children's transition into adulthood. There was a large disparity between their demands and capabilities. Parents' pile up of demands such as ensuring their children's financial stability and finding appropriate adult housing outweighed their capabilities, including available resources like Ontario Works. As a result of the aforementioned imbalance, parents reported on the QRS-F that they were, on average, experiencing moderate levels of perceived anxiety. Additionally, insufficient resources prevented adult children from transitioning into adulthood because they were forced to remain dependent upon their parents for financial and habitation related purposes. Adult children's difficulty managing major life changes further compounded their inability to leave their parents' home. Instead, the adult children remained permanently in the emergent adulthood stage of development (Arnett, 2000). To facilitate their children's transition into adulthood, parents discussed a need for adult resources that do not yet exist in Ontario.

4.2.1 Supports. The importance of supports for facilitating adaptation prompted the second research question pertaining to the supports parents deemed necessary to adapt to raising their children. This thesis has highlighted the importance of the availability of specific resources for family adaptation across children's lifespans. For example, the importance of a formal

diagnosis for service access was described by parents of both school age and adult children. Parents of both age groups (i.e., middle childhood and emergent adulthood) also reported demands relating to difficulty accessing services, and were lacking important formal supports like supervision services. Parents of adult children with FASD differed from the parents of school aged children in the second study because their children did not have the basic resources for survival in adulthood, such as housing or means for financial independence. In contrast, parents of children in middle childhood reported that the services they require do exist in Ontario, but they still need extended hours of those resources. The supports required to facilitate bonadaptation for both age groups as well as the differences in supports between them are discussed below.

4.2.1.1 Similarities between age groups. Obtaining a formal diagnosis was reported to have value for parents with regards to their children's qualification for services. Both ASD and FASD (depending upon an FAE or ARND diagnosis) are considered 'invisible disabilities' with no defining physical facial features, giving these individuals a 'normative' appearance (Hayes & Watson, 2013; Streissguth, 1994). Additionally, in the case of adults with FASD, they often grow out of any disability related facial features, making them even more difficult to diagnose (Streissguth, 1994). The lack of facial features means a formal diagnosis of FASD or ASD is imperative for service qualification because it can appear as if these individuals are making bad choices, rather than behaving in a way that is consistent with their disability (Chudley et al., 2005; Harder, 2009).

Furthermore, obtaining a formal diagnosis and qualifying for services did not ensure that parents' children had immediate access to services. All parents described lengthy waiting lists for a minimal number of services including, but not limited to, housing, respite care, behavioural

interventions (e.g., ABA), and personal skills training (e.g., social skills). Waiting lists were reported to be up to a year long. Parents of adult children with FASD described a lack of appropriate respite services that were chronically full or very expensive. In some cases, the need was so great that parents paid out of pocket for private services.

4.2.1.2 ***Differences between age groups*****.** In contrast to parents of school aged children with ASD and FASD who discussed wanting more of existing supports, parents of adult children with FASD reported a lack of basic services for their children. Almost all parents expressed concerns about a lack of appropriate adult housing and their child's inability to maintain employment, which are issues hindering their children's transition into adulthood.

According to the theory of Emergent Adulthood, the most important factors associated with transitioning into adulthood are the ability to accept responsibility for oneself, as well as establishing autonomy from parents with regards to decision making and finances (Arnett, 2000, 2001). Stable employment at a meaningful job can facilitate the aforementioned issues as well as assist emergent adults develop their adult identities (Arnett, 2000; Henninger & Taylor, 2014). Unfortunately, most parents reported that their children frequently changed jobs because they were let go due to FASD related behaviours, such as difficulty with staying on task. There are assisted employment services available in Ontario, but they pose significant barriers for adults with FASD because there is often a great deal of paperwork for job searching and applications which can be difficult for them to complete (Fetal Alcohol Spectrum Disorder Ontario Network of Expertise, 2015).

Parents also discussed a need for employers to be further educated regarding the symptomatology associated with FASD, so that they could provide a more supportive and stable work environment. Additionally, employment services frequently require a Developmental

Services Ontario qualification which is problematic for individuals with less severe FASD related symptoms who cannot qualify, or do not identify with having a disability. The burden of assisting their children attain and maintain employment frequently falls to parents (Fetal Alcohol Spectrum Disorder Ontario Network of Expertise, 2015). A lack of employment prevents adult children from achieving financial independence, and it can be difficult for them to afford to live independently.

Parents discussed the need for affordable and semi-independent housing so that their children could safely live out of the home. Addressing issues such as the availability of appropriate housing could potentially, as a natural consequence, resolve other stressors (e.g., risky behaviours) because the children would be more closely supervised. A lack of income and housing resulted in all adult children residing with their parents at least one point in time, a typical occurrence for emergent adults (Arnett, 2000). Although the age range of the adult children in the first study was 19 to 37, it appears that those adults were unable to transition from emergent adulthood to adulthood because they remained dependent upon their parents financially, and had trouble leaving the home. Addressing the gaps in adult supports and providing assistance navigating the adult system (e.g., providing a case worker) can improve service access for individuals with FASD, and potentially help adult children gain the resources they require to transition into adulthood (Freedman & Boyer, 2000). Additionally, according to the FAAR model, bolstering the aforementioned services would reduce the disparity between parents' capabilities and resources, thereby improving their level of adaptation.

4.3 The Larger Project and the Application of the FAAR Model

Use of a theoretical framework is necessary for stress and resilience research in order to provide structure and to conceptualize outcomes (Turnbull, Summers, Suk-Hyang, & Kyzar,

2007). The FAAR can be considered a resilience model because of the ongoing complex processes families undertake to restore balance between their demands and capabilities (Patterson, 2002b). It is commonplace in resilience literature for outcome-related terms to be used interchangeably (Turnbull et al., 2007). Adaptation, wellbeing, and family functioning are three terms that are typically used synonymously to describe family outcomes, and are only rarely properly defined (Turnbull et al., 2007). The use of the FAAR model allows for operationalized definitions of key factors for adaptation like resources, which can then be used for practical interventions (Megahead & Soliday, 2013). For example, social workers can use the FAAR model as a clinical framework to promote adaptation by therapeutically intervening to reduce parents' stressors (e.g., reduce child maladaptive behaviours) and to improve their resources (e.g., interfamilial relationships; Megahead & Soliday, 2013). Further details regarding family therapy interventions are provided in the Clinical Implications section.

Another strength of the FAAR model is that it comprises a range of factors related to adaptation including demands, capabilities, and meanings parents make of their experiences. Adaptation cannot be studied as a single construct because research has established that adaptation is a product of the integration of a multitude of factors, such as stressors and resources, that can change across time (Manning, Wainwright, & Bennett, 2011; Pederson, Crnic, Baker, & Blacher, 2015). Reflecting that theory, the FAAR model is cyclical, and theorizes that families often move in and out of the adjustment and adaptation stages across time (Patterson, 1988). Although this thesis was cross sectional (i.e., parents were interviewed at one point in time), the FAAR model provides a theoretical foundation for any changes in family adaptation within future studies. For example, if this thesis was replicated and parents' perceived stress scores on the QRS-F were significantly changed, the FAAR model can be applied to

interpret that finding as a result of the fluctuation in parents' demands, capabilities, and meanings across time. The aforementioned strengths provided the basis for the FAAR's selection as the theoretical framework for both this thesis and the larger project.

The larger project employed a battery of six questionnaires to examine different aspects of the FAAR model, such as families' demands, capabilities and meanings. The battery consisted of the Parenting Index- Short Form (PSI-SF; Abidin, 1995), the Questionnaire on Resources and Stress- Friedrich's short form (QRS-F; Friedrich et al., 1983), the Family Crisis Oriented Personal Scales (F-COPES; McCubbin et al., 1981), the Child and Behaviour Checklist (CBCL; Achenbach & Edelbroch, 1983), the Hope Scale (Snyder et al., 1991), and the Family Resource Scale (FRS; Dunst & Leet, 1987). Additionally, the semi structured interviews were informed by the FAAR model to capture any experiences that may have been missed due to the limited scope of the questionnaires. For example, one parent commented that her child's behaviours are always changing and that some questionnaire items (e.g., perceived stress level) varied according to the context. The ongoing project has applied the questionnaires and interviews to various populations, including different family types, family members, and developmental disabilities.

Research from the larger project focused in part on stressors related to raising children with ASD and FASD, such as externalizing behaviours (Watson, Coons, et al., 2013; Watson, Hayes, et al., 2013). The current study expanded on those results by focusing on capability-related resources that parents use to contend with those stressors. Parents' capabilities were examined using the FRS, which measures the presence of family resources and by employing the F-COPES, which measures parents' coping behaviours. Furthermore, the demands of the family were measured using the QRS-F, which measures parents' perceived stress levels. The same semi structured interviews as the larger project were employed. The interview questions

provided suitable information to answer the research questions and provided a complete picture of adaptation. In accordance with the larger project, the interview questions were informed by the FAAR model, and there were questions pertaining to parents' capabilities, resources and the meanings they make from their experiences.

The meanings individuals make are particularly appropriate for qualitative research. Meanings are a fundamental part of the basic interpretive approach, whereby researchers endeavour to understand how individuals make meaning of a situation at a particular point in time (Merriam, 2002). Similar to the FAAR model, the basic interpretive approach also posits that the meanings individuals construct change over time (Merriam, 2002). The analyses used in each study (i.e., IPA and Thematic Analysis) involved the examination of the meanings parents ascribed to issues surrounding raising their children (e.g., their children are unprepared for the future as adults), at times resulting in perceived stress

The FAAR model is also useful when used in association with the Emergent Adulthood Model, which posits that emergent adults are in a constant state of flux with regards to their relationships, housing, and finances (Arnett, 2000). The FAAR is cyclical and can therefore be used to better understand changing family dynamics when emergent adults frequently move in and out of the home, which can create demands that overwhelm the family resources. For example, an emergent adult moving back into the home may result in a period of crisis as the family struggles to redefine family roles and contends with a larger financial burden. Parents of adult children with FASD reported experiencing conflict with their children with regards to their roles within the family. Parents wished to maintain their managerial role as primary caregivers, but their children wished to assert their independence as legal adults and make their own decisions in the home. Issues such as domestic location were described by parents in vivid detail

during the interviews, and several methods were undertaken to maintain the quality of the analyses so that families' experiences were accurately reflected in the findings.

4.4 Ensuring the Quality of Mixed Methods Research

All research requires rigorous standards to ensure the credibility of its data (Fossey, Harvey, Mcdermott, & Davidson, 2002; Guest et al., 2012). During qualitative analysis, the researcher is considered to be the instrument of analysis, and therefore transparency regarding the analytic process is important to promote study credibility (Guest et al., 2012; Merriam, 2002; Smith et al., 2009). Qualitative researchers consider the use of quantitative research terms such as validity and reliability to be overly positivist and incongruent with qualitative analysis (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991; Lincoln & Guba, 1985). Instead of the aforementioned quantitative terms the expressions of trustworthiness, credibility, dependability, and confirmability are used in qualitative research (Lincoln & Guba, 1985). Merriam (1995) defined trustworthiness as how efficaciously a study does what it was originally designed to do. In other words, does the interpretation accurately reflect participants' experiences and context (Fossey et al., 2002). Several steps were taken throughout the analyses (i.e., Interpretative Phenomenological Analysis and Thematic Analysis) to make the analytic process as transparent and, by extension, as trustworthy as possible. The following credibility improvement strategies were undertaken: maintenance of an audit trail/code book, reflexive thinking as demonstrated in the reflexivity thesis section, member checking, and triangulation.

An audit trail, or code book, was maintained in order to record the definitions of codes, the procedures I followed throughout the analyses, and any decisions I made regarding issues like the combination of codes into themes (Guest et al., 2012; Merriam, 2002; Smith et al., 2009). In addition to the audit trail, I kept each draft of themes and their descriptions to provide

further detail regarding any changes. For example, one theme was eliminated completely due to redundancy and several others were relabelled as subthemes supporting a major theme. Although the attempt was made to remain as objective as possible when making decisions during the analytic process, my personal biases may have influenced those decisions, and therefore those biases must be taken into consideration. For example, an interest in parents' levels of perceived stress could act as a barrier to the acknowledgement of parents' strengths or positive outcomes during the analyses, and therefore that bias must be recognized as part of the research to promote researcher awareness and analytic transparency.

As the instrument of analysis, a researcher must provide a detailed account of their background with regards to education, experience and world views to provide context as to why and how the analyst might make meaning of the interviews (Guest et al., 2012). Please refer to the Chapter One for the complete reflexivity for this thesis. To ensure that the interpretations made were not unduly influenced by my own biases and were an accurate portrayal of participants' experiences, member checks were conducted.

Member checks are one of the strongest strategies to increase study trustworthiness (Guest et al., 2012; Lincoln & Guba, 1985; Merriam, 2002). At the conclusion of each interview, the researcher summarized the interview findings and then verified them with the participant. Additionally, at the conclusion of each study's analysis, all participants were sent a short summary on the findings, and were given the opportunity to provide feedback on the analysis. The majority of participants responded and generally confirmed the themes, validating the results. Two participants emphasized the importance of including themes such as a lack of adult jobs for individuals with FASD. Those participants' statements were then included in the analysis.

Participants' feedback was important as I did not personally conduct all of the interviews with the participants and was therefore sometimes working solely with interview transcripts, thereby missing an opportunity for feedback at the interview itself. To promote standardization, researchers from the larger project conducted the interviews I did not, ensuring all interviewers had similar training and background knowledge. When transcribing the interviews, researchers also included any noteworthy participant gestures, long pauses, or emotional reactions within the transcript to provide additional information. If there was confusion regarding a transcript, the researcher who conducted the interview was referred to, and the participant emailed for clarification if necessary.

Finally, this thesis is a mixed methods study and, as such, triangulation between the qualitative and quantitative data was made. Triangulation is the process of integrating different sets of research evidence to expound upon different aspects of a research question or phenomenon (Creswell, 2014; Denzin, 1978; Guest et al., 2012; Patton, 1999). The items that were selected from the questionnaires were analyzed after the interviews to prevent a focus on conversations confirming the questionnaire findings, thereby minimizing analytic biases. The questionnaire data supported the themes found for both studies. For example, parents of adult children with FASD discussed a fear for their children's futures during the interviews and that was also reflected in the QRS-F when all parents endorsed the item, "I worry what will happen to [my child] when I can no longer take care of him/her." Strategies for enhancing analytic credibility demonstrates to the reader that the results of a study are worthwhile to read and pose a valuable contribution to the field (Lincoln & Guba, 1985).

4.5 Considerations and Recommendations for Future Research

Although the methods employed were rigorous, there were several considerations to be made regarding the two studies, including the following: issues surrounding recruitment, inclusion of additional demographic information like socioeconomic status, and evolving diagnostic criteria. Suggestions for future research aimed at expanding on the results of this thesis are also provided below.

Families were recruited for both studies primarily through support groups as well as through disability-related Facebook groups. Support groups were used as the gatekeepers to access parents because they are a difficult population to contact, particularly when adult children move from child to adult services as they reach the age of majority (i.e., 18). Individuals who use support groups may be having different adaptive experiences than those who do not use support groups. Social support is a protective factor for adaptation, and therefore parents who do not use support groups are either in need of social support or have other means of fulfilling that need. It is also possible that parents who do not attend support groups are overwhelmed by other demands, rendering them incapable of mobilizing extra sources of social support.

Selection biases are common when using snowball sampling, whereby individuals are asked to refer other individuals to better access hidden populations (Salganik & Heckathorn, 2004). To promote transparency, participants were asked who they turned to for support (e.g., support groups, friends, or family members). Although many parents discussed attending a support group at least one point in time, not all parents were part of a support group at the time of their interview. Regardless of any selection biases, researchers have discussed the value of learning from resilient families to identify strengths conducive for good family functioning (Patterson, 2002b).

A second area for consideration is the necessity of additional demographic information. Two items that would have been of use were the level of education and socioeconomic status (SES). In both studies, more than half of the participants either forgot or declined to respond to the questions on the demographic questionnaire associated with SES and education. High levels of both factors have a positive impact on children's levels of functioning and life outcomes (Fountain et al., 2012; Paley et al., 2006). Families with greater financial resources would also have access to more services as they would have the means to pay for them privately.

Additionally, in both studies there was at least one missing item on questionnaires like the QRS-F, which prevented the calculation of total scale scores for some parents. There was information for the majority of participants for each question, but participants who did not answer may have yielded different results than those who did. Again, parents may have forgotten to answer or chose not to respond. Fortunately, it was possible for me to examine the questionnaires by individual item. Examining specific questionnaire items was useful for triangulating the quantitative results with the interview themes.

The final major area of consideration is the constant evolution of FASD and ASD diagnostic criteria (American Psychiatric Association, 2000, 2013; Chudley et al., 2005). Changes in diagnostic criteria may or may not influence changes in how individuals qualify for services. For example, in the current diagnostic manual Autism is now considered to be on a spectrum, whereas in the previous manual there were separate diagnostic categories (e.g., Asperger's) under the classification of Pervasive Developmental Disorders (American Psychiatric Association, 2000, 2013). Parents reported that even a slight change in the wording of a psychological report could qualify or disqualify a child for services. If supports are not changing the rules for qualification to reflect changing diagnostic criteria, parents may encounter

difficulties with accessing services for their children. Diagnosis has been reported to be a potential stressor for families (Watson et al., 2011). Future research regarding the impact of diagnostic changes on service access would be beneficial as professionals shift from one diagnostic standard to the next.

Another direction for future research is to include additional family members such as siblings to examine family resilience or adaptation. This study focused on parents' adaptation at an individual level. Research has shown that including family members and their perception of familial relationships in adaptation studies can paint a more complete picture of the complex adaptive processes (Pederson et al., 2015). In order to examine family resilience, at least two family members should be studied to allow for the inclusion of relationship outcomes (Patterson, 2002a). It may be that an individual parent may be struggling, but their family is functioning adaptively as a whole.

Recently there has been a shift in resiliency literature towards including siblings and their contributions to family adaption (Neece, Blacher, & Baker, 2010). Due to this shift to family inclusion, sibling research is currently being conducted as part of the larger project to better understand their experiences of living with a family member with a disability. Additionally, it has become increasingly important to gather further information regarding fathers' experiences with regards to family adaption (Crnic, Pederson y Arbona, Baker, & Blacher, 2009; Dabrowska & Pisula, 2010; Day, Lewis, O'Brien, & Lamb, 2005). This thesis was able to collect information from a total of 12 fathers of children with ASD and FASD, in comparison to 29 mothers. Of those 12 fathers, only half participated in the interviews and most of those individuals interviewed alongside their partners. Research including all family members' perspectives can help inform future clinical research and professional interventions.

A final area of future research is to study the interaction of adaptation-related factors across time (Pederson et al., 2015). Cross sectional research provides a snapshot of a family's demands and capabilities and cannot account for change processes (Patterson, 2002a; Pederson et al., 2015). According to the FAAR model, families move in and out of the adjustment and adaptation stages, implying that a family's level of adaptation changes over time (Patterson, 1988). Longitudinal research could assist in explaining changes in a family's level of adaptation (Patterson, 2002a; Pederson et al., 2015).

4.6 Knowledge Translation

An important aspect of academic research is knowledge translation. The most widely used definition of knowledge translation was put forward by the Canadian Institutes for Health Research (2015), "a dynamic and iterative process that includes synthesis, disseminations, exchange and ethically-sound application of knowledge to improve the health of Canadians, [and] provide more effective health services…" (para.4). The findings of this thesis largely pertain to available services in Ontario, and the results will be shared with all knowledge users through publications, presentations, and reports, as discussed specifically below.

For the purpose of this thesis, the knowledge users consist of other disability researchers, Children's Aid Societies (CAS), support groups, and families of children with ASD and FASD. The present research will be published in peer reviewed academic journals to add do the growing body of developmental disability literature. However, one of the barriers to knowledge translation is the accessibility of information, and not all knowledge users will have the knowledge of, or means to, access academic journals (Martin, Shooshtari, Temple, & Yu, 2010).

To promote information access for individuals outside of the academic community, a brief report containing the results of each study will be sent to all of the aforementioned knowledge users. Additionally, presentations were made at several conferences that cater to both researchers and professionals who work within the field of developmental disabilities. Lastly, research related to this thesis and the larger study were submitted in a letter of support for increased services for families of children with FASD in Ontario to the Legislative Assembly of Ontario in 2014. The dissemination of disability research is important not only for policy making, but for informing professionals of the issues most relevant to parents, so that formal supports can be tailored to their needs.

4.7 Clinical Implications

Research regarding families of children with developmental disabilities provides grounds for evidence based decisions regarding the creation, implementation, and adjustment of service delivery (Gambrill, 2010; Glascoe, 2000). Although there is currently research addressing behavioural and psychological interventions for children with ASD and FASD, there is little research focussing on interventions for their parents and family adjustment (Dykens, 2015). A recent review by Dykens (2015) found that only 11% of journal articles discussing interventions for neurodevelopmental disabilities included methods undertaken to reduce parental perceived stress or increase their sense of wellbeing. The lack of standardized interventions for families of children with developmental disabilities is concerning because in the first study parents reported that they, on average, felt moderately stressed. Studies addressing specific factors relevant to family adjustment such as parents' strengths, weaknesses, and the meanings they make about their situation can help inform the development of appropriate supports. For example, the aforementioned elements can be used to inform clinicians working with parents using Cognitive

Behavioural Therapy, which is oriented toward solving problems and learning new skillsets (Beck Institute for Cognitive Behavioral Therapy, 2015).

In addition to the importance of interventions for parents, this thesis also highlighted the necessity of an early diagnosis for children with ASD and FASD and its importance for gaining access to services. Individuals with FASD, many of whom are adopted, are at risk for not receiving a formal diagnosis due to the potential for a lack of information regarding their birth mothers' alcohol consumption during pregnancy (Chudley et al., 2007). Early screening for diagnosis and/or less stringent qualifying service criteria should be implemented for the FASD child welfare population. Adult services and clinical interventions specific to FASD in Ontario are severely lacking, despite research indicating that individuals with FASD require lifelong services (e.g., psychosocial care) regardless of their diagnosis (Spohr & Steinhausen, 2008).

Parents also discussed the need for service providers to gain a better understanding of ASD and FASD. Parents of school aged children with FASD discussed a lack of knowledge in the school system and a general need for the education of medical professionals with regards to FASD diagnostic criteria. Parents of children with ASD reported that although teachers were knowledgeable about their children's disability, there was still a need for training in gold standard interventions like Applied Behavioural Analysis. Educating professionals is crucial for the successful implementation of early childhood interventions, which can reduce the likelihood of future secondary disabilities (Streissguth et al., 1997).

In conclusion, this thesis has expanded on knowledge gathered through the larger project pertaining to the experiences of families raising children with ASD and FASD (Watson, Coons, et al., 2013; Watson, Hayes, et al., 2013). Employing the FAAR model as a theoretical

framework has allowed this research to gain a better understanding of how parents use their capabilities (e.g., parent advocacy) to cope with demands (e.g., a lack of appropriate adult housing), and the meanings they make from those experiences (e.g., fear for their child's future). Furthermore, this thesis comprises two studies that highlight the needs of parents raising children with ASD and FASD at different stages of development, including middle childhood and emergent adulthood. Understanding parents' needs can help inform professionals (e.g., support groups, therapists and medical professionals) who assist families of children with ASD and FASD experiencing maladaptation. Research has shown that parents can act as protective factors for their children's secondary disabilities and therefore require supports to continue assisting their children successfully move forward through the developmental stages from infancy to adulthood (Streissguth et al., 2004, 1997).

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Appendix A

APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS

Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New X / Modifications to project / Time extension

Name of Principal Investigator and school/department	Jenna Pepper (Psychology) Shelley Watson (Psychology – supervisor)
Title of Project	**Adoptive Parents Raising Children with Developmental Disabilities**
REB file number	2013-09-03
Date of original approval of project	November 17, 2013
Date of approval of project modifications or extension *(if applicable)*	
Final/Interim report due on	November 17, 2014
Conditions placed on project	Final report due on November 17, 2014

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate REB form.

In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best of luck in conducting your research.

Susan James, Chair Laurentian University Research Ethics Board

Appendix B

Interview Guide for Parents

1. Describe your child. What is he/she like? Favourite memories?
2. What is it like for you to be his parent?
3. Please describe a typical day in your home (Prompt- can you please run me through the morning routine, etc.)
4. How did you find out about your child's disability? (Prompt- when did you suspect he had a developmental disability?)
5. How did you feel when you received the diagnosis of FASD?
6. What prompted you to initiate the diagnostic process?
7. What meaning did you think a formal/differential diagnosis would provide? (Prompt: why did you want a formal diagnosis?)
8. Please describe, in as much detail as possible, the story of your diagnostic experience, giving particular attention to the critical events and challenges you have faced along the way.
9. What was the most helpful during this process? What was the most difficult part of the process?
10. How did your child cope with the testing? What about other family members?
11. Is there anyone whom you turned to for support during this process?
12. How was having a name for the disability changed the experience for you?
13. Please talk about how you are doing right now

a) Whom do you turn to for support?
b) How do you manage all of your responsibilities?

14. Tell me how you manage your child's FASD at home.
15. If applicable, tell me about how school personnel manage your child's FASD.
16. How do your child's doctors manage your child's FASD?
17. What has worked to facilitate effective management of your child's FASD? Why?
18. How do you think family dynamics are different having a child with FASD? (Prompt: if applicable, does one child get more attention than another? Have your vocational choices been influenced by your child's disability?)
19. In what ways have you changed and in what ways do you see yourself differently as a result of your child having FASD?
20. When you think about the future, what do you see?
21. If you could wave a magic wand, what supports would you like?
22. If you could give advice to another parent with FASD, what would you tell them?